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THE UNIVERSITY OF ALBERTA

LIVING WITH AIDS : COUNSELLING NEEDS

by

ANNE MARIE MADOTT

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF EDUCATION

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled LIVING WITH AIDS: COUNSELLING NEEDS submitted by ANNE MARIE MADOTT in partial fulfilment of the requirements for the degree of MASTER OF EDUCATION in COUNSELLING PSYCHOLOGY.

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Date Oct. 5, 1990

Dedicated to

My Mother

Lillian Mary O'Rourke

ABSTRACT

What are the counselling needs of individuals directly affected by the AIDS epidemic? From a counselling perspective the important features of the disease are those that shape the experience of being threatened by the AIDS virus. An interpretation of these aspects of the disease requires exploration beyond biomedicine to the fears, beliefs and values that make the experience of AIDS. The study approaches this question with the view that the individuals directly affected by this phenomenon are best suited to outline the aspects of their experience that could enhance understanding of the counselling needs.

A review of related literature provided a synopsis of the etiology and pathogenesis of the AIDS virus, epidemiology in general with specific reference to youth, women and the heterosexual community. The neuropsychological and psychosocial aspects of this epidemic, as well as counselling intervention models, are subsequently reviewed.

The overall goal of this research project was to gain an understanding of the needs and processes encountered by individuals affected by the AIDS epidemic and to synthesize this information to further our understanding of counselling needs. The methodology used to attain this goal took the form of a qualitative design and responded to three objectives.

The first was to document the lived experience of this small, varied sample, to enhance understanding. The second objective was to identify themes and personal perceptions of counselling needs from the perspective of individuals living with AIDS. The final objective was to provide an opportunity for these individuals to share and others to learn what it means to be living with AIDS.

Eight individuals were interviewed with a semistructured interview format, as the primary instrument for data collection. The content analysis approach provided the bases for the interpretive framework.

The five major themes that emerged were a need to talk, stigma, fatigue, death and dying and services needed. Patterns and relationships raised questions and highlighted the need for further research in the areas of gender differences, counselling and personal growth, personal guilt and issues of death and dying. The main overriding theme that all participants advocated was the need for counselling.

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My mother, to whom this work is dedicated has always been a stronghold in my life, on whatever road I chose. My daughter, Lilia, whose frequent hugs and gentle presence has fueled my every step in this process.

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CHAPTER I
INTRODUCTION TO THE STUDY

Counsellors and caregivers within the health care community often initiate, decide, plan and deliver services and caregiving regimes based on the adoption and modification of preexisting models. We integrate our knowledge of theory and skill and are then able to apply this to research and client benefit, always cognizant of the human tendency to personal bias. Undergriding these integrated competencies must be "an intentional awareness of one's worldview and how that worldview may be similar to and/or different from the worldview and personal constructions of the client and other professionals" (Ivey,Ivey & Simek-Downing,1987).

It was with this in mind that the question of what shapes the personal experience of living with the Acquired Immune Deficiency Syndrome (AIDS) arose. What are the counselling needs of individuals directly affected by this epidemic? How can the health care community be of assistance to help soften the devastating and overwhelming burden inflicted by this disease? Coupled with this was the view that the individuals directly affected by this phenomenon are best suited to outline the aspects of their experience that could enhance understanding of the counselling needs.

It was from this frame of reference that this study was initially conceived. A need for this type of research was considered and objectives designed. A review of the literature supported such a study and the methodology needed to approach this area from the perspective of individuals living with AIDS seemed best suited to a qualitative design.

The term 'people living with AIDS' is used throughout this study to include those individuals who are directly affected by the AIDS virus, either through infection or their personal relationship with a loved one who is infected. Additional terms that relate to this phenomenon are defined as they are used.

Need For The Research

AIDS (Acquired Immune Deficiency Syndrome) is the subject of considerable misunderstanding and fear. This is evident in the many misconceptions that surround those who are infected with the causative virus, Human Immunodeficiency Virus (HIV). The AIDS virus continues to be regarded as a 'gay' disease, a 'self-inflicted' plague, a consequence for a lifestyle that has now involved innocent victims. These misconceptions continue to stand in the way of greater social understanding and acceptance of those affected, limiting any efforts at psychosocial intervention and psychotherapeutic aid.

Everyone who is sexually active, outside of a relationship in which both partners have been monogamous since about 1977 and are uninfected, is at risk of exposure to HIV. People who received blood or blood products between 1977 and November 1985 and intravenous drug users who share needles are also at risk. This involves a frightening number of people.

On a worldwide scale, the HIV epidemic is still spreading rapidly to males and females, adults and children. No longer is it possible to compartmentalize and categorize this disease as affecting minority subgroups. AIDS is not confined to one or two segments of society. Evidence indicates that the AIDS epidemic has mutated and exploded to the extent that

no group is immune. Clearly everyone must learn the facts about AIDS; education, at present is our most effective weapon against this disease. Caregivers, counsellors, psychotherapists, social workers, psychologists, psychiatrists and all members of the helping community must be well informed and skilled in their endeavors to assist on social, medical, practical and emotional levels.

Yet, what does it mean to have AIDS? The HIV virus and the disease AIDS have become an intensely researched medical phenomenon. The range of medical and psychosocial knowledge continues to grow. From a counselling perspective the important features of the disease are those that shape the experience of being threatened by the AIDS virus. An interpretation of these aspects of the disease requires explorations beyond biomedicine to the fears, beliefs and values that make the experience of AIDS. It is in that maze that the psychological and counselling needs of those affected can be found.

However, little has been written from the perspective of persons with HIV or those suffering from AIDS, and their loved ones. This knowledge must be given an opportunity to be communicated and shared. Individuals who are infected with the virus, or have developed AIDS, as well as their loved ones possess a wealth of knowledge from lived experience that is invaluable to an understanding and provision of psychotherapeutic intervention.

Purpose Of The Study

The purpose of this study was to probe and delineate the psychological factors and counselling needs as perceived by people living

with AIDS. The research design is qualitative in nature, designed to search out important variables and to study a new phenomenon. A semi-structured video/audio taped interview, utilizing an interview guide was the primary instrument for data collection.

The overall goal was to gain an understanding of the needs and processes encountered by individuals affected by the AIDS epidemic and to synthesize this information to further our understanding of counselling needs. The interpretive framework utilizing content analysis to systemize, analyze and synthesize the data, provided for the identification of themes, personal processes and patterns involved in coping with this epidemic.

Research Objectives

The research was guided by three objectives; two which were empirical in nature and one which fell outside the realm of research.

1. To document the lived experiences of a small, varied sample of those individuals affected by AIDS in an effort to increase understanding and dispel prevailing misconceptions, specifically within the caregiver, counsellor community.

2. To identify the psychological themes and personal perceptions of the counselling needs of individuals affected by the AIDS phenomenon.

3. To provide an opportunity for persons affected by the AIDS phenomenon to share their knowledge and lived experiences in a meaningful and constructive fashion.

Delimitations

The purpose of this study was to delineate a number of self-perceived needs of individuals living with AIDS from a small number of individuals.

Secondly, the sample was selective and was restricted to Canada, specifically the Ottawa area.

Finally, this study was intended to draw out some of the issues and needs, from the perspective of a very select group. It is exploratory in the hope of identifying salient factors for further research. The goal of documenting emergent themes is seen as beneficial for increasing understanding and developing counselling methodology.

Overview of the Study

The remaining chapters of this thesis are as follows:

Chapter II provides a backdrop for the research and overviews the areas of AIDS research that are relevant to the goals and objectives of this study. First, a synopsis of the etiology and pathogenesis of the AIDS virus is provided. This is followed by a section on epidemiology in general and the areas of youth, women and the heterosexual community. The neuropsychological and psychosocial aspects of this epidemic, as well as counselling intervention models, are subsequently reviewed.

Chapter III outlines the research design and methodology utilized for the collection and analysis of the data. Ethical procedures are specified, as is a discussion of the consequences and possible implications of the researcher as the instrument of data collection.

Chapter IV contains a presentation of the findings and conclusions of this study in accordance with the three research objectives.

Chapter V consists of a discussion of these findings and explores potential avenues of future research.

CHAPTER II

RELATED LITERATURE AND RESEARCH

Etiology and Pathogenesis of the AIDS virus

The majority of the research on AIDS has been in the biomedical area. The fatal nature of this disease has warranted intense scientific action with regard to etiology. Although no cure has been found as yet, much is now known with regard to etiology and the spread of the AIDS virus (Corless & Pittman-Lindeman, 1988 ; Feldman & Johnson, 1986). This section is intended to give a brief introductory overview of the current state of knowledge of the Human Immunodeficiency Virus (HIV), the identified cause of AIDS.

AIDS is an acronym standing for "Acquired Immune Deficiency Syndrome". It is caused by a virus of the retrovirus family, the Human Immunodeficiency Virus (HIV). This viral hypothesis, which is currently in popular acceptance, initially gave this virus two separate names due the political nature of its discovery. The American research team claimed the virus was HTLV-III, a distant relative of the HTLV (human t-lymphotropic virus) discovered by the National Institute of Health. The French named their version of the virus LAV (lymphadenopathy associated virus) declaring their discovery a year before the American teams' was announced. An international commission changed the name to HIV (human immunodeficiency virus) eliminating the confusion caused by the two names for the same entity (Gallo and Montagnier, 1988). However, while

HIV is the agreed name today, it is still sometimes referred to under names used in the past- HTLV-III, LAV, ARV.

HIV belongs to a broad group of viruses called retroviruses, a virus coded in the RNA of a cell as opposed to the DNA of a cell. Although the name HIV suggests a single entity, it is now known that there is not a single HIV but a family of viruses each with distinct characteristics e.g. HIV-II, HIV-II (Hall, 1988). The biological properties and molecular structures of retroviruses is thoroughly reviewed elsewhere (Fauci,1988; Hall, 1988). However, it is the case that the etiology of AIDS and the exact characteristics of the Human Immunodeficiency Virus still present a formidable challenge to scientist.

What is known, is that the HIV virus invades cells which bear the necessary viral receptor site on their surfaces. This site is called the Cd-4 antigen. Chief amongst these cells are white blood cells, the T4 or T- helper cells. T-helper cells act to switch on the immune system when the body is under attack by infectious agents (Batchelor,1988). The virus particle itself consists of a core of genetic material, the blueprint for the virus to reproduce itself. This core is in the form of a double stand of RNA. Attached to the RNA is a special enzyme unique to this group of viruses called reverse transcriptase (Fauci,1988). Around the core are two concentric cases of protein and then outside of them a layer of lipid, essentially fat. This lipid layer must be attached for the virus to be able to survive outside a host cell. A large number of things can damage this lipid membrane or envelope, including heat, hand soap, bleach and a whole range of disinfectants (Fauci, 1988).

Thus, the virus is fragile and easily killed when outside a host cell. Infection occurs almost entirely through direct exposure to semen or blood (Fauci,1988). Although HIV has been isolated in body fluids (saliva, tears sweat, urine), it is extremely low in quantity and as such thought to be of no danger. Thus, HIV invades a cell which carries the CD-4 antigen on its surface then changes the genetic composition of the cell it enters and subsequently destroys. Once a person is infected the virus becomes a part of the makeup of the cells of that person.

Most people infected with this virus do not know that they have been infected. It takes at least 8-12 weeks for a detectable antibody to appear in the blood. During the period between infection with the virus and the appearance of antibodies against it, routine antibody tests will be negative, however viral antigens are present in the blood and the virus may be cultured from body fluid. The individual at this stage is potentially highly infectious even though the antibody blood test is negative (Fauci,1988; Hall, 1988).

At the time that antibodies against the virus appear in the blood, detectable antigens disappear from the circulation and do not reappear for an indefinite period of time. The subsequent reappearance of these antigens in the blood suggest increased viral replication and is associated with a deterioration in the clinical state of the patient (Fauci, 1988; Levi, Bredesen & Rosenblum, 1985). When the antibodies do appear in the blood some people experience glandular-fever-like illness, usually mild but sometimes quite severe. This is the so called 'seroconversion illness'. The illness eventually disappears and the patient becomes well again. These

people then experience no evidence of being infected yet would test positive for antibodies against the virus and are said to be 'asymptomatic positives'. and are able to pass on the virus to others.

Individuals may continue to stay in the asymptomatic stage for years after infection continuing in good health. However a portion of individuals will progress, experiencing fevers or night sweats, loss of weight, a feeling of malaise and a lack of energy. These individuals are described as having AIDS- related complex (ARC). Examination of the blood of those with ARC shows a pattern of gradual reduction in the number of T-Helper cells in their blood (Fauci,1988). At the same time antibody levels against the virus, start to fall. It is thought likely that as individuals start to become ill, they again become even more infectious to others (Hall, 1988).

There is undoubtedly an overlap between having AIDS and having ARC. The broad spectrum of HIV may be viewed as a continuum of immune system damage without sharp, artificial dividing lines. Yet, the distinction between AIDS and ARC is a very real one in the minds of many individuals. A person is diagnosed as having AIDS when one of the following three criteria is met: opportunistic infections, opportunistic tumors or AIDS dementia (CDC, 1987).

Neuropsychological Aspects

The pathogenesis of the human immunodeficiency virus (HIV) is commonly complicated by the central nervous system (CNS), as well as, peripheral nervous system (PNS) disorders. The Acquired Immunodeficiency Syndrome (AIDS) Dementia Complex (ADC) is a severe and progressive dementing neurologic disorder. It is characterized by

disturbances in cognition, motor performance and behaviour; as the disease progresses, global dementia accompanied by subacute encephalitis, vacuolar spinal cord degeneration, and meningitis are often observed (Levi et al., 1985; Navia, Jordan & Price, 1986; Tross & Hirsh, 1988; Wolcott, 1986). Although ADC often occurs in the presence of secondary opportunistic pathogens, it can occur in their absence and occasionally prior to measurable immune dysfunction (Levi et al, 1985:; Navia et al ,1986; Wolcott, 1986).

Estimates of neuropsychological dysfunctions in persons with HIV infection range from 25-80%. At autopsy 60-80% of patients dying with AIDS have pathological changes in the brain caused by the HIV virus (Boccellari, Dilley & Shore, 1988; Levi et al, 1986; Navia et al.,1986). Additionally, studies have shown that ADC will present as the first manifestation of AIDS in 25% of patients (Levi et al,1986; Macks, 1986).

The observation that neurologic dysfunction does occur in the absence of any noticeable systemic disease or immune dysfunction suggests that HIV probably invades the central nervous system relatively early after initial infection. This is supported by the presence of HIV antibody in the cerebral spinal fluid early in the disease course (Macks, 1986; Navia et al, 1986; Wolcott, 1986). How or when the virus gains access to the brain and the mechanisms governing HIV pathogenesis in the nervous system are as yet unclear.

Clinically, patients with ADC often present with symptoms that resemble those associated with depression and anxiety. There is a similarity to the cognitive, affective, behavioural and somatic components seen in

major affective disorders. In addition, some individuals develop an organic psychosis (Boccellari et al.,1988). Early recognition of symptoms and accurate diagnosis is important as many have experienced relief of symptoms from treatment with Azidothymidine (AZT) (Kaslow & Francis,1989).

In recognition of the extreme frequency with which AIDS dementia complex (ADC) is clinically observed, the Centers for Disease Control (1987) changed the inclusion criterion for individuals who would receive an AIDS diagnosis. As changed, the current criteria now include ADC as a disorder that warrants an AIDS diagnosis.

Epidemiology

The rapid spread of AIDS, on a small scale, is demonstrated by the efforts required to provide this research with current prevalence rates. During a six month period actual numbers of AIDS cases have increased by approximately 33,000 worldwide, 13,000 in the United States and 500 in Canada. In a recent article in the Toronto Star (1990), Michael Merson, director of the World Health Organization Global Program (WHO) on AIDS is reported as stating that "it is very unlikely that the global prevalence of HIV infection will stabilize or level off for at least several decades" (pA21). The current projection by WHO, as recorded in the Toronto Star (1990) that 20 million people will have been infected by the year 2000, "is expected to be pushed up by a rise in heterosexual transmission of the disease in industrialized countries" (pA21).

Presently, the World Health Organization estimates that 5-8 million persons are infected with the HIV virus worldwide, most of whom live in

subsaharan Africa and the Caribbean (Digest,1989; Toronto Star, 1990). Demographic statistics in the U.S. in 1988 estimated that 1.5 to 2 million were infected with the HIV virus and 50,000 with the AIDS or ARC (Corless & Pittman- Lindeman, 1988).

Most recently in an AIDS Update, The Toronto Star (1990) reported 228,874 cases of AIDS worldwide; 128,319 total cases of AIDS in the U.S.; and a total of 3,818 Canadians have been diagnosed with full-blown AIDS, 1,536 of whom are still alive. In Ontario 1,501 cases have been reported, 453 of whom are still alive.

In Alberta 222 cases have been reported to date, 60% of whom are in the Calgary area (Thomas, 1990). In Edmonton 24 individuals were reported as having AIDS in 1989, which is double the 11 cases reported in 1988, with a total of 64 cases reported since 1983 (Thomas, 1990). The executive director of AIDS Network estimates that 2,500 to 5,000 persons are infected with the HIV virus in the Edmonton area (Farrel,1990). It is little wonder that some describe AIDS as a soft nuclear bomb that threatens the survival of the human race.

It is imperative to note that these figures are not restricted to gender or age. In the Toronto area 40 teenagers are infected with AIDS (Moloney,1989). A recent study found high rates of the HIV virus in women in Montreal. "One in every 394 women who gave birth in Montreal early this year was carrying the virus that causes AIDS. . . That makes Montreal's female infection rate higher than San Francisco's (one in 777 women) and lower than New York's (one in 77 women)" (Tougill, 1989). These prevalence rates warrant further discussion.

Youth and AIDS

A recently published report by a Queen's University research team addresses youth's knowledge, attitudes and behaviour with respect to AIDS and other sexually transmitted diseases. The Canada Youth and AIDS Study (King,1988) surveyed a sample of 38,000 young people aged 11 to 21 in Canada's ten provinces and two territories. One of the findings is that, although the threat of AIDS has precipitated anxiety among young people, it has not substantially affected their sexual behaviour. The study shows that an "alarming number" of young people who are sexually active engage in behaviour through which infection can be transmitted.

Statistics on AIDS cases provided by the Federal Centre for AIDS indicate that 12 people between the ages of 15 and 19 have developed AIDS by June 1989 and 553 between the ages of 20 and 29 (Radford, King & Warren,1989). These numbers are not indicative of the number of individuals with the AIDS virus due to a possible ten years asymptomatic period. Given this possible incubation time, a large proportion of this 20 to 29 year old population with AIDS contacted the virus in their adolescent years. It, therefore, seems likely that as many or more young people in their teen years are presently infected with the HIV virus.

A Vancouver study involving 549 participants, aged 14 to 19 years, found a 3 percent prevalence rate of HIV infection (Rehart, Chan, James & Barnet, 1989). A Toronto study reported 86 cases of HIV infection in an under 20 category; half of these teens were 15 and younger (Central Toronto Youth Services AIDS Project, 1989).

Women And AIDS

The World Health Organization estimates that 1.5 million women worldwide are infected with the AIDS virus. The majority live in Subsaharan Africa and the Caribbean (Digest,1989).

Seventy-nine percent of women with AIDS are 13-39 years of age and within their childbearing years (Guinon& Hardy,1987). AIDS has become the leading cause of death of young black women in New York state and New Jersey and is speculated to be the fifth leading cause of death among all U.S. women of childbearing age by 1991 (Associated Press, 1990).

Virtually all women with HIV infection are heterosexual and thus, have the potential for transmission to a sexual partner. Twenty-one percent of women who now have AIDS acquired it via sexual transmission from infected men, and 28% of all men with AIDS are themselves heterosexual, thus placing their female partners at potential risk (Chu, Buehler & Berkelman, 1990).

Wofsy (1987) outlines a number of issues that women confront as infectees and proposes that these issues must be addressed when proposing and organizing programs for women with the AIDS virus. First, there is a profound sense of isolation and a lack of community support. Second, a profound sense of grief exists for the loss of health, body image, sexuality and childbearing potential. Thirdly, women may be too sick to fulfil their duties as parents. Lastly, this disease has thus far predominantly affected men, and women may consequently find it difficult to find primary care physicians and other health care professionals who are equipped and

educated in the issues that relate specifically to women and who are, thereby, sensitive to their needs.

Heterosexuals and AIDS

The evolving epidemiologic pattern of human immunodeficiency virus (HIV) infection and AIDS makes it clear that all segments of our population are at risk. Yet, denial is most evident in the acceptance and awareness of heterosexual transmission.

Initially, AIDS was recognized among homosexual men and among heterosexual men and women who were intravenous drug users. Sexual transmission from men to women was considered unlikely or uncommon. However, this misconception was rapidly dispelled as evidence of sexual transmission of the HIV-1 was documented (Guinan & Hardy, 1987). Additionally, epidemiologic evidence now, also confirms that transmission can occur from female to male (Chu et al, 1990). Centre for Disease Control (1987) indicates that most cases of AIDS are homosexual or bisexual men, heterosexual intravenous drug users, blood transfusion recipients, patients with hemophilia or other coagulation disorders. However, 2,981 individuals with AIDS, (1,281 men and 1,700 women) have been reported as heterosexuals who denied intravenous drug abuse and reported no previous blood transfusions.

There have still been fewer heterosexual men with AIDS reported in the United States and Canada than homosexual or bisexual men. There are several possible explanations for this difference. First, the average number of sexual partners reported by homosexual men with AIDS is much greater than the number reported by heterosexual men with AIDS (Guinan &

Hardy,1984). A greater number of sexual partners increases the chance of exposure. Second, the cumulative incidence of AIDS has been greater in the homosexual male population than in the heterosexual female population, thereby increasing the risk of HIV infection for each random, anonymous sexual encounter. Third, the sex acts practiced by homosexual men, specifically, receptive anal intercourse may be more efficient in transmitting the virus than vaginal intercourse practiced by most heterosexual men (Stall, Coates & Hoff, 1988).

It is clear that the Human Immunodeficiency virus has already been effectively seeded throughout most of the world, causing substantial morbidity and mortality. It does not distinguish or have a preference to age or gender and a continuance and increase of this pandemic can be expected. Each segment of the society and ultimately each individual must take some responsibility.

This diversity of gender and age is not reflected in the literature. To date the studies of psychosocial factors related to AIDS has focused on the homosexual community. The heterosexual community has been virtually ignored and there exists little clinical research to guide the mental health professionals who will undoubtably be assisting growing numbers of persons affected by the AIDS pandemic.

Psychosocial Research

The area of psychosocial research, in relation to the AIDS phenomenon, has not been a major focus of attention since the detection of this disease six years ago. Studies in this area often discuss the clinical spectrum of AIDS from the clinicians' perspective, either through a) the

use of case studies or theoretical models (Volberding, 1985; Nichols, 1985); b) discussion of psychosocial principles useful in understanding and treating individuals with life-threatening illness (Wolcott, 1986); c) the discussion of the effects of societal attitudes and scientific pronouncements (Brett, 1985).

General psychosocial stresses associated with life threatening illnesses such as cancer impede an individual's level of adaptation in all areas of life. Wolcott (1986) delineates numerous stressors common to life threatening illnesses. Undoubtedly these psychosocial stressors are relevant to the AIDS/HIV individual. However, AIDS/HIV infection and its related conditions have a constellation of unique characteristics that generate a unique series of stresses for patients, their loved one, spouses and family members, as well as health care professionals and employers (Nichols, 1985; Voldering, 1985; Wolcott, 1986).

AIDS is a communicable, sexually transmitted, lethal disease. It was first identified and still occurs most frequently in socially stigmatized groups: homosexuals and intravenous drug users (Kaslow & Francis, 1989). Nichols (1985) distinguishes the psychosocial reactions of persons with AIDS/HIV into two primary problems; one a result of the disease itself, the other societally induced. Features specific to the AIDS epidemic that contribute to the unique psychosocial and medical aspects of this disease are as follow (Batchelor,1984; Cassens,1985; James,1988; Holland & Tross, 1985; Rubinow, 1984; Tross& Hirch,1988; Wolcott,1986).

Psychosocial and medical stigmatization include:

1. The diagnosis of AIDS/HIV may force the person's identification as a likely member of a stigmatized minority.

2. The social stigma and fear associated with the contagious aspect of the disease can cause avoidance of physical and social contact by others, sometimes including the person's family.

3. Due to moral disapproval and negative societal attitudes towards homosexuals and intravenous drug users, there is a tendency to blame the infected person for the disease in these two largest transmission groups.

4. Health care professionals and services for people with AIDS (PWA) are overwhelmed by the problems associated with AIDS; additionally, there may be a lack of knowledge and sensitivity among health care workers that is detrimental to care.

5. The disease has had a highly visible social and political impact. There has been considerable media attention that is not always accurate and is often stressful and aggravates public fears which leads to attempts at repressive measures such as quarantines.

The disease process itself adds other particular and pervasive stressors.

1. There is an uncertainty of knowing whether or not infection with HIV will lead to the development of AIDS.

2. There is an additional uncertainty about the infectious nature of the disease with respect to transmission to others.

3. The age of the population affected by HIV/AIDS is usually young.

4. AIDS is associated with the highest incidence of neurologic and neuropsychological morbidity of any serious common illness not primary to the central nervous system.

5. AIDS is associated with severe chronic physical disability which leaves persons debilitated and disfigured.

6. Transmission of the virus in utero makes HIV infection in women a major concern. The health of the woman and the infant, delivered in the context of maternal infection, are implicated.

Fear, uncertainty and a preoccupation with confidentiality, are the natural responses by society, the scientific community and individuals that result from the many societally induced psychosocial stressors peculiar to the AIDS epidemic.

Counselling Interventions

Despite the well documented and detrimental psychological consequences of AIDS/HIV infection, little clinical research has yet appeared to guide mental health professionals and assist in intervention strategies to ameliorate distress among affected persons (Macks, 1986). Morin, Charles & Maylon (1984) and Morin & Batchelor (1984) reported that whereas medical needs of people diagnosed with AIDS were being met, psychological needs were not . AIDS patients are at high risk for psychological problems that are often not diagnosed and under treated (Perry & Tross,1984). The counselling research that does exist, falls into the following groupings: prevention (Hearst & Hulley,1988; Jarlais & Friedman,1988; Paul,1989; Peterson & Martin,1988); risk reduction and behaviour change (Becher & Joseph,1988; Fisher,1988; Stall, Coates & Hoff,1988) and pre and post counselling for HIV testing (Soskolne, 1988). An overview of the psychological research on HIV/AIDS covering behavioural,

cognitive, psychobiological and neuropsychological issues can be found in Baum & Nesselhol (1988).

Research, in this area, does provide basic information about psychosocial and psychophysiological functioning and provides a basis for intervention, care and prevention. Consequently, a number of different intervention strategies do exist, most of which are based in preexisting models of reaction and interventions in terminal illnesses in general.

The majority of authors suggest a multidisciplinary team approach that emphasizes the need for psychosocial assistance in the form of group or individual counselling. Green and Miller (1985) present a model that fits this description. The population is divided into a number of main target groups: a) those with AIDS and ARC ; b) those who are asymptomatic HIV seropositive; c) those concerned about acquiring AIDS i.e. worried well; d) family and friends. Each of these groups function as support groups. Psychiatric and psychological services are available on a consultation bases.

Wolcott (1986) offers a model providing services for affected individuals, family, friends and supportive health care professionals. There is no provision for psychosocial assessment and psychiatric and psychological services are provided on a consultation bases.

Volberding (1985) offers a medical and psychosocial model dividing the care of individuals into early and late stages of the disease with psychiatric issues addressed and general emotional support given.

Lomax and Sandler(1988) supply a model of psychotherapy and consultation with persons with AIDS, developed out of the work of Dilley

(1984). This model emphasizes prevalent psychosocial issues as related to stages of the disease process; specifically, diagnosis, stabilization, deterioration and terminal stages, stressing the need for a substantive therapeutic relationship and a systems approach to assist the individual in dealing with the extensive number of people in his life (i.e attending physician , psychiatric consultant , primary nurse etc).

Morin and Batchelor(1984) saw issues of loss and bereavement as important topics that must be addressed by people with AIDS, their partners and significant others.

Thus, there are several models proposed for the intervention and psychotherapeutic needs of individuals involved in the AIDS epidemic. However, none seem to satisfy the requirements of total care nor are they comprehensive in nature. However, some do take into account some of the particular features, from a medical and psychosocial point of view, that are peculiar to the AIDS epidemic.

AIDS mental health issues have, to date, received less attention due to the magnitude of the medical crisis and subsequently, the psychosocial field has been forced to look at preexisting models and theories of reactions and interventions in terminal illnesses to attempt to meet the needs of this population. It does, however, seem from a review of the psychosocial literature that there are features of the HIV/AIDS phenomena that differ and perhaps, broaden the boundaries of the needs of individuals afflicted by other terminal illnesses.

Summary

Epidemiological studies confirm that the AIDS crisis is unconfined and that the number of AIDS cases will continue to increase. Counsellors will face an increasing number of individuals, including infected infants and children, struggling to cope with this devastating illness. Revision will need to be made in providing health services. It is apparent that the future will require greater involvement on the part of counsellors, psychologist, social workers, nurses, psychiatrists and the world at large. Comprehensive intervention programs will be needed to meet the needs of the growing numbers of individuals involved or affected by this pandemic. Above all, an understanding, as profound as possible of the lived experience of having AIDS is essential.

CHAPTER III

DESIGN, METHODOLOGY AND ANALYSES

Research Design

The overall goal of this research was to gain an understanding of the needs and processes encountered by individuals affected by the AIDS epidemic and utilize this information to develop a useful tool to further our understanding of counselling needs. The research design is qualitative, designed to search out important variables and to study a new phenomenon.

Both qualitative and quantitative research methodologies have characteristics that are ideally suited for some investigative questions and inadequate for others. If the object of the discovery process is to explore and discover the needs and experiences of individuals from their perspective rather than to determine the frequency of predetermined linkages or to test hypotheses then the preferred methodology is qualitative (Borg & Gall, 1989; Brenner, Brown & Canter,1985). However, qualitative research is not viewed, herein, as superior nor a replacement for empirical research, but simply as more compatible with the purpose of this study. This choice does not preclude the possibilities of quantitative design in future research to verify or expand the information acquired through this process.

The nature of the information required to access the psychotherapeutic needs of individuals affected by the AIDS phenomenon is extremely intimate and personal. As such the methodology and procedures utilized must be uniquely designed. The interview as a research technique

is noted for its adaptability, permitting greater depth in data collection (Borg & Gall, 1989). This is viewed as imperative to address this topic adequately.

The semi-structured interview is reasonably objective and permits an understanding of the individuals' opinions. This technique utilizes an interview schedule that consists of a predetermined set of procedures and a core of structured questions from which the interviewer branches off to explore areas in depth. This provides the opportunity to probe for underlying factors or relationships which are too complex or personally threatening to access in more straight forward questioning. Additionally, the use of audio/video technology allows for a non interrupted process and the opportunity for thorough analysis and future utilization as an educational tool.

The choice of an appropriate method of data collection must be in keeping with an equally appropriate method of data analysis that suits the research objectives. The content analysis approach was viewed as most appropriate as its overall purpose is "to identify specific characteristics of communications, systematically and objectively in order to convert raw material into scientific data" (Brenner et al, 1985, p.117). Ultimately, an understanding of meaning through the scrutinizing of any regularities that occur in terms of themes or concepts was sought. In addition to discovering the meaningful relationships in the data, an understanding of roles, lifestyles and values unfolds when utilizing this approach to analysis. This provides a rich understanding of the experiences of individuals living

with AIDS from their perspective and affords a better opportunity to assess and equate this information to counselling needs.

As with any type of scientific data analysis procedure, the results of content analysis must meet basic requirements. Holsti (1969) outlines three basic requirements which form the bases for assessing the reliability and validity of this research. First, the data and subsequent analysis must be free from analyst bias and thereby possess objectivity. Secondly, the analysis must be systematic, designed to secure data relevant to the scientific problem. Finally, the sample must be representative of the relevant domain and possess applicability.

Sample

Initially, subjects were sought through liaison with the AIDS network of Alberta and medical specialists in the field of infectious diseases. An attempt was made to involve a heterogeneous group consisting of individuals of differing age, sex, and lifestyle orientation. The proposed ideal was a minimum of one individual of each gender from each of the following categories: a) tested HIV positive; b) diagnosed with AIDS/ARC; c) significant other (family, loved one) of an individual infected with the HIV virus; d) significant other (family, loved one) of an individual diagnosed with AIDS. This would provide for eight subjects.

This approach, however, proved unsuccessful. Availability proved to be an obstacle in recruiting a heterogeneous sample in Alberta. Nevertheless, a serendipitous series of events did provide for an appropriate sample. The HIV clinic at the Ottawa General Hospital in Ottawa, Ontario

through liaison with Drs Gary Garber and William Cameron agreed to recruit individuals for this research project.

The Immunodeficiency Clinic at the Ottawa General Hospital is a multi-disciplinary team approach for the immuno-compromised individual. The goals of the clinic, as stated in their brochure (1990), are to offer specialized assessment and treatment for the HIV infected individual; to provide up to date treatment; to ensure safety to those on monitored drug programs; to address the psychosocial and spiritual needs of patients, friends and families; to promote out of hospital care versus in-hospital management whenever possible; to provide liaison with family physicians and community services; to provide HIV education for patients' partners and family members, as well as hospital personnel; and to further research towards a cure for AIDS and prevention of infection. Team members include medical, nursing, social work, psychology, pastoral and dietary personnel.

The individuals recruited by the clinic included six females between the ages of 21 and 55 years and two males, 25-45 years, respectively. This combined grouping provided a sample that consisted of a female and male partner of individuals with AIDS; two female partners of individuals who are HIV positive, asymptomatic; two females who are HIV positive; and a male and female with AIDS (Appendix A). Confidentiality is of major concern and consequently identification is by first name only and may be a pseudonym.

Michelle is a woman in her late twenties who is HIV positive, asymptomatic, whose husband has AIDS. Shawn, also in his late twenties, is HIV negative and his partner has AIDS. Simone is in her middle to late

thirties, she is HIV negative and her husband is HIV positive. Arlene is a woman in her middle fifties, she is HIV negative and her husband is HIV positive. Lucie is in her early twenties and is HIV positive and is beginning to display symptoms. Lynne is a twenty one year old women who is HIV positive, asymptomatic. Susan, a woman in her middle thirties and Andre, a man in his early forties both have developed AIDS.

Each of these individuals was interviewed utilizing the procedures specified in the subsequent section. Interviews were all audio and videotaped with the following exceptions. The interview with Lucie was audio taped only and the interview with Lynne was in note form.

Data Gathering Procedure

A semi-structured video/audio taped interview, utilizing an interview guide was the primary instrument for data collection. The interview as a research tool, as previously discussed, is well suited to the objectives of this research project. One of its main purposes, as an exploratory devise, is to identify variables and relations, to suggest hypotheses and to guide other phases of research. Yet, it is imperative to consider the possible sources of error and distortion which may occur in this method of data collection. An example is that the contact between the interviewer and the interviewee is face to face and intensive which allows for the opportunity of bias to occur. Consequently, a number of measures were taken to avoid and minimize bias.

Specifically, an interview guide (Appendix B) was developed and utilized in each interview situation. Specific guidelines for interviewing were established to ensure that all respondents were exposed to a similar experience.

Interview Guide

The interview process involved three steps: a review of the goals and purpose of this study, obtaining informed consent, and a semi-structured interview consisting of eight core questions (see Appendix B).

The first step in the interview process was to review the goals and purpose of this project. The following statement to the subjects was designed to set the parameters and provide an understanding of the process : "The purpose of this study is to look at and document the psychological factors (mental/emotional/ spiritual and behavioral) and the counselling needs of individuals who are seropositive or have developed AIDS and their significant others. The goal is to gain an understanding of your needs from your perspective; to pull out the aspects of your lived experiences so that caregivers and the counselling community may learn from you in order to better serve and aid you and those in similar situations. Your knowledge of what would and could benefit you and others is invaluable to an understanding of your needs and the providing of psychotherapeutic and counselling assistance and intervention."

The second step was to obtain informed consent. The procedure as outlined in the ethical section of research format was adhered to and outlined on the consent form (see Appendix C).

The participant was then asked to comment on a series of core questions from which the interviewer branched off to explore topic areas in depth. This provided the opportunity to probe for underlying factors or relationships which were too complex or elusive to encompass in more straight forward questions.

The interviewers' style of behaviour while interviewing was task oriented and supportive with an expressed sympathetic understanding towards the participant. Brenner et al (1985) describe this as a socio-emotional style of interviewing and suggest that it is a "prerequisite for adequate information reporting, particularly when sensitive, personal topics are involved"(p.124).

The development of questions initially involved study of the AIDS phenomenon, followed by consideration and review of the dimension of the interview necessary to respond to the research objectives. The scale of the interview involved a small number of participants. The scope was very focused in content area, yet, time lines proceeded from retrospective to a futurist view of life experiences. In an effort to gain a holistic view of the counselling needs of these individuals, it was considered necessary to address human functioning and need on an emotional, physical and spiritual sphere. As such, each question addresses at least one of these areas of functioning at some point along the time line. Effort was made to present clear and unambiguous questions and still provide room to elicit different frames of reference. The funnel approach was utilized to organize and priorize these questions on the interview guide. Specifically, the most general question was asked initially, moving to the more specific. This provided a general focus for the participants as they adjusted to the interviewing situation. The interview guide consisting of the interview procedures and the core questions is located in Appendix B.

Ethical Procedures

In any research project, a plan must exist to ensure that ethical standards and legal requirements are established that meet the criteria set for behavioural science research. This is particularly true in the area of AIDS research. Issues of informed consent, privacy, confidentiality and anonymity are of paramount concern. Consequently, ethical guidelines for research with human subjects as outlined in Annex H of the Social Sciences and Humanities Research Council of Canada and the Guide for Research with Human Subjects, University of Alberta, Faculty of Education formed the bases for the consent form (Appendix C). The ethical procedures that follow were approved by the Research and Ethics Committee of the Department of Educational Psychology, University of Alberta.

Participants met with the researcher before any research commenced. The nature and purpose of this research was explained to the participant to ensure that consent was given or withheld advisedly. Participants were advised of their right to privacy which extends to all information on a person's physical and mental condition, personal circumstances and social relationships. This gives the individual the freedom to decide when, where, in what circumstances and to what extent their personal attitudes, opinions, habits and eccentricities are to be published. Additionally, it was outlined that in this study, there was to be a probing of private personality and affairs as the intent of this research was to document the perceived psychological needs of the participant.

With regard to confidentiality and anonymity, the consent form provided for a clear understanding between the researcher and the

participant as to the extent that the acquired information would be kept confidential in the original and future use of the data. The option of three possible consent agreements were reviewed: consent form I, consent form I with additional addendum or consent form II (Appendix C). Provisions were in place for exercising the right to withdraw at any time. During the interview process the participant needed only to advise the interviewer of this wish. At other times the participants could exercise this right by advising the researcher in writing of their intent at the address included on the bottom of their copy of the signed consent form. Informed consent was obtained in writing. Thus, the written consent set out the following: a) purpose of the research; b) benefits envisioned; c) possible consequences; d) procedure to be used; e) rights of the participant; f) name of persons eliciting and giving consent.

Analysis and Interpretation

Content Analysis provides a rich and firm basis for understanding human experience when the data are in the form of verbal responses to open ended questions (Brenner et al, 1985). The procedure for analyzing data, utilizing this methodology, initially involved a period of immersion. The video and audio tapes were viewed and listened to and all notes reviewed. The focus was on sensitivity to new ideas and relationships, as well as patterns between inferences and the nuances of feeling in voice tone and body language. Notes of impressions were made. An examples of an interview transcript is included in Appendix D.

The next stage involved the selection of categories, which is considered the key to content analysis (Brenner et al, 1985). In this case,

these categories are described as themes, in keeping with the objectives of this study. They are exhaustive and mutually exclusive which will enhance reliability. This was accomplished by labelling and coding each response utilizing a color code representative of each category as it presented itself. While going through the data the quality of the response and clarity was evaluated. Review of the information gathered in these two steps provided for the emergence of subthemes and patterns.

The next step involved a synthesis of this material. Patterns, relationships and key concepts or major themes were considered and assessed which, in turn, led to an interpretation of the material. Thus, the data were sorted, labelled, coded and ordered in the form of themes. As could be expected, a structure naturally emerged which allowed for an interpretation of relationships and patterns.

Reliability and Validity

The difficulty with methodologies used to adapt the empirical concepts of reliability and validity to qualitative research is well documented (Borg & Gall, 1989; Holsti, 1969; Krippendorff, 1980; Lincoln & Guba, 1985). Although the approaches vary, there is agreement that procedures to assess the adequacy of data acquisition, analysis and results are essential and must be systemized.

Holsti (1969), as previously stated, outlines three basic requirements which form the bases for assessing the reliability and validity of this research. First, the data and subsequent analysis must be free from analyst bias and thereby possess objectivity. Validity increases with the minimizing of bias and reliability increases with objectivity. Secondly, the analysis

must be systematic, designed to secure data relevant to the scientific problem. Finally, the sample must be representative of the relevant domain and possess applicability.

The concept of reliability addresses the question of whether the data obtained in the research provide a trustworthy basis for drawing inferences and making recommendations (Krippendorff, 1980). Similarly, a judgment of validity answers the question of whether the instrument used was an appropriate one for what needs to be discovered. Thus, the data gathering methodology, in this case the interview guide and procedures was implicated.

A number of measures were taken to avoid and minimize bias. The interview guide was developed and utilized in each interview situation. Specific guidelines for interviewing were established to ensure that all respondents were exposed to a similar experience. The interviewer's style of behaviour while interviewing was task oriented and supportive utilizing a socio-emotional style of interviewing.

The funnel approach to positioning questions in the interview guide and a semistructured approach to the interview process enhanced the design's capabilities to address the research objectives. More valid responses are obtained by allowing the participants to return to, to the same topic as memory is stimulated. Freedom to probe vague responses and the provision of a relaxed atmosphere that is not stressful is conducive to remembering and sharing emotionally laden content material.

The participants chosen did qualify as having the knowledge and experience sought in the research goals and thereby met the criteria for

selection validity. Their involvement and experience with the AIDS epidemic is representative of gender variation, lifestyle orientation and age, with the exception of the pediatric and adolescent population. Consequently, the results can be thought to be generally applicable in this domain.

Researcher as Instrument

The researcher observed, interviewed and was the key instrument in data collection. The possibility of bias occurring is a real and a major consideration in determining the trustworthiness of the results. This is especially true when the topic of discovery is in an area that is immersed in psychosocial, political and ethical debate. The nature of the information sought is emotionally laden and fraught with differing value perspectives. The researcher's attitude, belief system and personal view of differing lifestyle orientations are important factors to consider.

This researcher approached this investigative study with the subsequent attitude and preconceptions. The AIDS virus has no gender preference. The sample recruited was specifically designed to incorporate individuals of both genders and differing lifestyle orientations to assist in dispelling the myth that AIDS selectively affects homosexuals and intravenous drug abusers.

The researcher's personal view of homosexuality and differing lifestyle orientations is one of acceptance. The fact that this virus was initially detected and remains in the largest concentrations within the homosexual community is relevant to the psychosocial aspects of discovery. However, the focus by many, on the numbers involved in this stigmatized

minority group has created a dichotomy of guilt and innocence; those who through their own choices and behaviours have contracted the virus and those who through no fault of their own have been infected.

This researcher rejects division of these, seemingly, mutually exclusive groups and perceives only victims. Guilt and innocence is not the issue. The morality of behaviours associated with the acquisition of the AIDS virus is not the focus or concern of this study. A demonstration of this perspective is evident in the absence of interview questions on specifics pertaining to lifestyle, sexual preferences and how the virus was contracted. The participant was free to share this information if he/she chose but it was not requested.

The content of the interview process involved in securing the data was very emotional and the researcher was not beyond being affected. In addition, this researcher views counselling as valuable and essential to prevent and manage the psychological morbidity arising from fear of and knowledge of HIV infection. In addition, the researcher is more familiar with a counselling interview than a research interview. Thus, conscious effort was required to remain in the interviewing mode and not enter into a counselling process with the participant. This was aided by the use of the interview guide.

CHAPTER IV

RESEARCH FINDINGS

The overall goal of this research project was to gain an understanding of the needs and processes encountered by individuals affected by the AIDS epidemic and to synthesize this information to further our understanding of counselling needs. The task of data collection seemed best suited to a semistructured interview format. The sample, consisting of eight individuals, was varied in gender, lifestyle orientation and experience with the AIDS virus. Content analysis was employed to systematize, analyze and synthesize this information. This interpretive framework provided for the identification of themes, personal processes and patterns involved in coping with this epidemic.

This chapter presents the findings of this research and is organized around this study's objectives. Each of the three objectives are presented in their original form and the pertinent findings are reported. Interpretations of these results are inherent in the process of this qualitative design.

Information pertaining to the lived experience of each participant, as self-disclosed, has been analyzed and synthesized. It is subsequently presented in response to the first objective in a detailed but condensed form, beginning with the participants whose partners are HIV infected and followed with those whose partners have AIDS; next, the participants who are HIV infected; and finally, those participants who have AIDS.

Effort was made to sketch these very personal and intimate disclosures in a holistic fashion. It is important to note that participants

shared as much of their personal experience as they chose. Questions were not focused on situational and circumstantial details and the interviewer remained within the format of the interview guide. Consequently, the reader may find that they are left with questions as to the how, when, where and why in varying degrees, differing with each participant.

The second objective addresses the main themes that emerged from the data. These are subsequently organized as subheadings within the objective II section of this chapter. The third objective is responded to with references to the participants' evaluation and feedback to the interview process.

It is often the case that important results do not stem from the initial objectives and so it is in this case. As such, the last section of this chapter addresses these findings.

Objective I

To document the lived experiences of a small, varied sample of those individuals affected by AIDS in an effort to increase understanding and dispel prevailing misconceptions, specifically within the caregiver, counsellor community.

Simone

This articulate and expressive woman, in her early forties has been married for six years. Her husband, of comparable age, was confirmed as HIV positive, four years ago. She continues to be HIV negative and is a palliative care nurse. This couple have no children, however, it had been their plan to have a family but this is no longer considered feasible. and is a source of pain for Simone.

The manner in which Simone and her husband discovered that he was HIV positive is a source of concern for Simone. They received a letter from the Red Cross blood donor clinic, expressing concern with regard to her husband's blood. The request was for him to contact his family doctor. At this point, the possibility of HIV infection never occurred to Simone. Subsequent tests by their family doctor confirmed she and her husband's HIV status. Simone feels that these events and the manner in which they occurred were very impersonal.

Neither Simone, nor her husband have been involved in any type of counselling and she does not acknowledge a personal need for intervention that is of a clinical nature. Her stated view with regard to the possibilities of infection is that "I'm a fatalist. If you're going to get something, your going to get it . . . ". She notes that she and her husband "do not always talk about it" but that it does "come out in other ways, such as frustration. We just carry on and have a good life and we enjoy what we have". However, she does wonder if this will change when and if her husband's health status changes. He is presently asymptomatic and well. Doctors indicate that it will possibly be two years,at least, before he will likely show symptoms.

Tears and laughter endured throughout the interview. Simone stated that this was the first time that she had talked about her situation and expressed appreciation for the opportunity.

Arlene

Arlene, a nurse in her early fifties, is married with grown children. She is well informed and straight forward in her presentation of her life

experiences with the AIDS virus. Her husband, a hemophiliac, was discovered HIV positive six years ago. Arlene continues to test negative.

A number of Arlene's family members are infected with the AIDS virus; her husband's brother, two nephews and a niece. She notes that it is more difficult for herself and her husband to cope with the younger members of their family being infected and ill.

Arlene believes that coming to terms with the reality of being infected with this virus is a gradual process. Her husband is presently asymptomatic and she anticipates many life changes when his status changes. Presently, they focus on maintaining normalcy. Neither she nor her husband received any counselling initially. She is, however, presently involved in a woman's group process for partners of hemophiliacs. She finds this support very helpful.

Shawn

This very expressive, sensitive and professional man of thirty years is the partner of an individual with AIDS. They have been together for approximately six years. Shawn's partner discovered he was HIV positive nearly a year ago when going for a routine examination after feeling unwell and run down for some time. He continues to be able to work but is ill periodically. Shawn continues to test HIV negative. Their family doctor, who is also a personal friend was involved from the beginning and Shawn believes this was helpful in dealing with the initial shock.

However, he does comment that a person thinks he has "fairly reasonable knowledge, awareness . . . but when it becomes you . . . all the worst things jump out at you . . . and it doesn't matter what you thought, it

doesn't matter what you read . . .". Shawn and his partner are both involved in individual counselling. He initially thought that he didn't need this type of help but now both he and his partner find that it is essential and very helpful.

Shawn was very open and expressive in sharing his thoughts, frustrations and the ups and downs involved in sharing your life with a loved one who has AIDS. He was able to identify and articulate his needs from an emotional and pragmatic framework. He identifies the support he receives from friends and family as a major source of strength and experiences a sense of community.

Michelle

Michelle is a woman in her early thirties. She is HIV positive and married to a man who has AIDS. They discovered that they both carried the antibody for the AIDS virus within the first year of their marriage, approximately three years ago. Michelle states that she contracted the disease from her husband who has most likely been carrying the virus, unknowingly, for some time. He is unaware of how he became infected and according to Michelle, feels responsible for her being infected, believing that others judge him.

It is only recently that Michelle's family are aware that Michelle and her husband are living with AIDS. Michelle comments that this does make it a little easier, however, her mother, whom she is closest to, does not know. She was visibly very sad as she shared that her father had recently died and that she is being protective of her mother by not telling her. This is

obviously very difficult for Michelle as her mother's support is important to her.

Michelle, who is asymptomatic, continues to work and care for her husband at home, on her own. He has been unable to work for the last year and a half and is presently very ill. Michelle spoke of her personal lack of hope and her inability to discuss death and dying issues with her husband. She speaks of her life after her husband's death with despair. She has never been involved in counselling, and shares her pain with the only friend in whom she has confided.

Lynne

This young woman of twenty one years, recently tested positive for the AIDS virus. She has had one intimate relationship in which she is no longer involved. She is asymptomatic and lives with her parents who are the only people who are aware the she is HIV positive with the exception of the medical professionals involved.

Lynne was extremely reticent and would not allow the interview to be video or audio taped. Discussion of her experience with the AIDS virus was very painful and disturbing for her. She is physically very well, at this time and anticipates remaining this way for some time as she is convinced that she only contracted the virus a short time ago. She is hoping that new developments in dealing with this virus, medically, will be advantageous for her, in the future.

Lucie

Lucie, in her early twenties, is a single mother raising a four year girl, on her own. She is HIV positive and is beginning to develop symptoms.

Lucie states that she has had one intimate relationship with a young man who previously was an IV drug user. She continues to see this man whom she states that she loves and believes that he is also HIV positive, although he will not allow himself to be tested.

A deep anger and distrust of the medical profession was pervasive throughout the interview. She expressed difficulty in understanding the specifics of this virus as related to her present condition even though she notes that the doctors and nurses have "tried to explain it" to her on numerous occasions. She states that she tries "not to think about it".

Nevertheless, Lucie did confide that she was " very shocked and upset" when she found out. She is not involved in any counselling and believes the remedy for the situation is " to be strong and fight this thing" and goes on to explain that being strong means not showing any emotion (ie crying). Fighting involves making oneself get up, even when feeling poorly, eating well and keeping busy. Only Lucie's parents are aware of her situation and her mother is her primary support. Her only hope is that she should live till her daughters' sixteenth birthday. She does worry that her daughter could contract the disease but refuses to have her tested.

Susan

Susan was diagnosed with AIDS three years ago. She is thirty years old. Her fiance, a hemophiliac, died of AIDS four years ago. Susan nursed her fiance through to his death; she was HIV positive at that time and developed her first pneumonia one year after he died.

Susan's courage, compassion and sincerity were evident throughout the interview. She lives on her own and continues to work. She is, however,

often in hospital for periods of time but continues to struggle to be self supporting. She is not involved in any counselling and receives some emotional support from her sister and her fiance's family.

At one time, shortly after her fiance died, she made contact with the local AIDS network and offered to be a volunteer. She let them know that she was HIV positive and that she had cared for her fiance whom had died of AIDS. At that time she was very healthy and energetic and hoped that she could help others in some way, even if it was just picking up groceries for someone that was unable to do so for themselves. Susan states that she was told no "because you are female" and they didn't think she " could relate to (their) patients of whom the majority are men". She was very disappointed and continues to believe that there is a difference in the support experienced by men and women.

Appendix D contains a transcript of this interview.

Andre

Andre, an articulate man in his early forties has been living with AIDS for three years. Fatigue, general weakness and breathing problems precipitated his visit to his doctor and being tested for the antibody. He states that he was convinced that he was negative and when told the results instantly panicked. Although his doctor took time to explain the details of his situation to him, he does not remember this occurring. He appreciates that this doctor contacted him later in the evening to ensure that he was alright.

He emphasized the need for counselling from the beginning of any investigation that might lead to the discovery of a person carrying the AIDS

virus. He indicates his belief that it is essential for an individual to accept the realities of their situation in order to live effectively with AIDS. He claims that one of the factors that contributed to his first opportunistic infection was his not talking about his illness after he initially was told that he had the AIDS virus. He is convinced that his silence and withdrawing into himself aided the virus.

Andre is involved in a support group for individuals living with AIDS. He is actively involved in the AIDS network in the Ottawa area and has recently decided to become more public in this work. He indicates that people living with AIDS need to be more open so the disease will be more accepted and the myths associated with it being a "sex or gay disease" can be dispelled. He notes that much work remains to be done and that there is still a stigma fed by peoples' view that AIDS is a shameful disease. He believes that the needs for individuals living with AIDS are very similar to any other terminal illness but that it is this stigma that impedes the developing of the services that are presently not available.

He speaks of the changes that have occurred for him in the last period of time with excitement and enthusiasm. He claims his priorities have changed and that he now has a more complete understanding of himself. He states that for him "AIDS was a blessing because I now understand myself better . . . before I was lost".

Objective II

To identify the psychological themes and personal perceptions of counselling needs of individuals affected by the AIDS phenomenon.

This section delineates the main themes synthesized from the data. Sixteen subcategories became visible as the data was analyzed (Appendix E). These were colour coded and charted for more detailed analyses. This eventuated in a culmination of five major themes. Each of these themes are subsequently discussed with supporting dialogue from participants.

Need for Talk

Perhaps, the major theme that emerged from the data was the need to talk. All participants clearly expressed this need as being primary, either using these words or variations on this theme. Lucie and Michelle simply state a person "needs someone to talk to", while Andre extends this to "getting sick when I don't talk". Arlene describes this as "a need to care and share with another person . . . and sometimes to sound off". Susan, Simone and Lynne echo this same notion and support for the need of verbal exchange. Shawn sums up this necessity when he states:" sometimes you just need people, just to talk to, just plain talk . . . somebody just to say all the thoughts that you feel . . . there are just things ".

Another component to this theme is understanding. This idea of understanding, expressed by all participants except one, refers to situational difficulties and specificities peculiar to living with AIDS, as well as an appreciation of self and active caring by others. This is considerably different from a societal understanding or appreciation indicated subsequently in the notion of stigma.

Susan describes this in very concrete terms when she states: ' just a little bit of understanding that if I'm tired and can't do something that they accept that . . .". Andre extends this concept to include a need for a realistic

appreciation of a situation and how it affects what the individual needs to cope with at that given time. He describes the understanding he experiences from his sister when he states, "she understands and gives me the love I desperately need . . . she tells me she loves me and hugs me . . . spends time with me and talks . . . I feel secure". Shawn couples this need for understanding with gaining a personal perspective on one's experiences and feelings and asks the question, "should I be feeling this?"

This additional perspective of understanding and self perspective broadens the theme of a need to talk to include a notion that resembles counselling. The majority of the participants (six out of eight) received no counselling initially. At the time of interview, four were involved in either an individual or group process. However, all participants in their discussion of their need to talk and be understood either directly stated or alluded to the need for professional intervention to some extent.

The specifics and the design of counselling processes as stated by the participants is discussed in detail later in this section. However, with reference to this theme, it is important to note that this need for verbal exchange to promote wellness and personal understanding extends beyond the notion of chit chat and banter to an intimate exchange of sharing, caring and self discovery.

Stigma

A number of variables factor into this theme of reproach or disdain. The first is the notion of secrecy, which all participants, in at least one area of their lives, describe. This need for secrecy is referred to by Lucie when she states " no way my girl friends or any friends are gonna know . . .

nobody is going to know about this , you tell them that - they're gonna flip on ya, man - the word is gonna get around . . . next thing you'll have to move. So, I just keep it to myself." Susan simply says :"I don't really want to share my secret with anybody . . ." Michelle believes that if the people at her workplace knew that she was HIV positive they would be afraid of her and not speak to her. Other examples involve not telling family members. Simone notes that although she has told her family of her husband's illness, he has, to this point, chosen not to share it with his family. Shawn cautions on the need to be selective with regard to whom and how much one shares and the possible dangers associated with confiding this type of information with individuals associated with one's place of employment.

The repercussions of this excessive privacy naturally leads to seclusion. All participants, with the exception of the two partners of individuals who are HIV positive and asymptomatic, relate experiences of social isolation, to some degree. Andre and Shawn describe how their social circles have become smaller and more selective. Lucie, Lynne and Michelle, all HIV positive, have concluded that new intimate relationships are not feasible for them. Lucie very candidly states, "you can't make love to another man". Susan expands this restriction, commenting that she is not experiencing the prejudice as much anymore because " I haven't been social or going out very much . . . I meet people and start to get close . . . if it gets too close I back away . . . a lot of people don't understand." Michelle's social involvements have been limited to a small number of family situations which she now attends without her husband.

The exception to this was Arlene whose husband is a hemophiliac. She claims that secrecy is not an issue for her and describes herself as being "aggressive and not shying away" and that she hasn't " met rejection yet". "People are much more tolerant and educated on the topic". However, she concedes that there is a stigma associated with being homosexual and witnessed the need for secrecy when her niece became ill with AIDS. In addition, when asked if any of the women in her support group for partners' of hemophiliacs are HIV positive, she commented that "some of them may be HIV but I don't know . . . ".

Trust issues stemming from a fear of others not understanding form a broader perspective on the theme of the stigma associated with living with AIDS. " A lot of people don't understand what it's about" and consequently there is a worry that if " they didn't know how to deal with it, (I guess) a person could be really scared off by it . . . ". Lucie notes that she can trust her boyfriend "cause he has it too - he understands". Shawn states that friends " don't know . . . they don't know what to say . . . or how to say it, they don't understand what your going through . . . you don't know how they're going to react".

A fear of contagion adds still another dimension to this theme. All participants identified this aspect of the social and personal stigma of AIDS. For some it involved sexual contacts which do present a very real risk. For others the fear was associated with people backing off if they knew. " A lot of people don't understand . . . you can't get it by touching me or talking to me . . .", states Susan. Michelle explains this fear that she believes others have of her by telling the story of when she is visiting with her family and

her young nieces and nephews are around and they offer her a drink from their glass. She does not take it because she feels that this would upset their parents. She is also very careful to only kiss them on the cheek which she also believes is necessary to remediate the fears of her family members.

Lucie speaks of the difficulty she experienced finding a doctor that would perform elective surgery after she informed them that she was HIV positive. In addition, Michelle recounts a visit she and her husband made to a doctors' office in which they were greeted by a doctor wearing layers of gloves and a mask. And on another occasion being refused treatment due to a physician's worry that if his other patients were to find out their health status that he would lose clients.

Fatigue

The implications of fatigue on infected individuals and their loved ones were recounted by all participants experiencing any symptomatology associated with this virus. In the extreme, the two individuals who are living with full blown AIDS describe a pervasive fatigue that affects their everyday tasks and commitments. Partners of those individuals with the AIDS virus and who are asymptomatic, speak of their disappointment and the need for them to be tolerant when their partner " is just too tired to participate in something", when that individual seems well in all other respects.

Although this theme appears unidimensional in comparison to the previously discussed categories, the implications from a psychological perspective are many. Relationships on a personal, social and career level are threatened as the individual's ability to reciprocate and follow through

can be severely jeopardized. Quality of life is continually threatened as the individual looses initiative and is progressively unable to partake in everyday activities.

Death and Dying

A variety of factors contributed to this theme which was addressed by all the participants in some form. For two of the individuals, a fear was expressed; a "what if - it scares me the ways of dying, like how it might be . . .". For the two individuals who are HIV negative and partners of individuals living with AIDS, a fatalistic view of dying was shared, highlighting its inevitability for everyone. The third perspective on this theme was one of avoidance. "I don't think about death" or "I try not to talk about dying". "Move quickly" and "keep busy" were commonly used phrases.

Four of these individuals were able to share the loss felt when a friend or a loved one died of AIDS. They described it as " the worst experience" since their involvement in the AIDS phenomenon.

The religious dimension of this theme was addressed by all with a clarity of response. Four participants affirmed that religion in a formal organizational sense was very important and helpful to them, aiding them in their ability to cope. The other four clearly indicated that religion had no place in their life. All participants were more willing to discuss the effect of death and dying on their personal goals than from a religious or spiritual perspective.

For four of the six female participants, the inability to have children was cited as a major loss. Anticipatory grief of the loss of loved ones preceded a sense of hopelessness, in one case. " After my husbands' death I

have no life left - I can't rebuild . . . another relationship is not possible". In another, hopelessness springs from a loss of future goals. " When I really look at my life there really is no goals, there's nothing towards my future that I'm building myself . . . it's not worth the effort". For three of the participants there is a clarity of purpose, a change of priorities and although long range planning is no longer possible, a genuineness is expressed. " My approach to people and relationships has changed . . . in some ways AIDS, for me, has been a blessing".

Services Needed

All participants, with the exception of one, were able to describe what they viewed as the type of treatment services needed for people living with AIDS. An integrated service that involved a variety of professionals including medical personal, legal specialists, psychologists, social workers, nutritionists and spiritual counsellors. Most participants noted the difficulties that people living with AIDS have coordinating and finding the energy and time necessary to access the services needed. For most fatigue is a major factor in varying degrees, as is arranging time from work with employers on a regular and frequent bases. Thus, a centralized service could facilitate and remediate these difficulties, to some extent.

The need for counselling, initially and throughout the process, was indicated. There was a suggestion that the approach would be best received if it were more personal and less clinical. The idea of a format that would involve clients in the organizing and provision of services through a process of networking was intimated. A design that would afford the opportunity to seek practical, pragmatic assistance from the professionals

(ie. the drawing up of a will, practical hints with regard to financial concerns and funeral arrangements), as well as emotional support and direction, information and individual and group counselling for individuals living with AIDS and their family were described.

Honesty and a clarity of explanation was requested of all professionals involved, with specific reference to medical personnel. Services for women were suggested and thought to be severely lacking. A need for francophone services was also indicated and understandable considering the region in which this study took place.

Objective III

To provide an opportunity for persons affected by the AIDS phenomenon to share their knowledge and lived experiences in a meaningful and constructive fashion.

The participants were provided an opportunity to express, in their own fashion, what they considered to be the aspects of their lived experience that caregivers and the counselling community could benefit from knowing. Their knowledge of what would and could benefit themselves and others was considered invaluable to an understanding of the needs and the provision of counselling and intervention.

All participants, in a variety of ways, provided the interviewer with feedback that indicated that they were grateful and appreciative of the opportunity to participate. Michelle confided that although she feels hopeless with regard to her personal situation, she chose to be involved hoping that her experience and the sharing of her pain could benefit others. She expressed a 'worthwhileness' with regard to the process. Simone

noted that it was the "first time (she) really talked about it" and "felt better". She expressed her appreciation for the opportunity. Susan's parting comment was that it was " nice talking to you, you made me feel very comfortable".

Andre was quite candid about becoming a little tired of being involved in research and not experiencing any change as a result but noted that he would continue in the hope that it could make a difference. Similarly, the remainder of co-researchers believed that their perspective mattered and wanted to be a part of the process involved in addressing these issues.

Patterns and Relationships

This last section of this chapter, which reports the findings of this study, reviews those patterns and relationships that emerged outside the framework provided by the objectives of this study. These results are considered important and therefore, warrant discussion.

The first pattern begins to emerge in the review of the 'need to talk' theme and culminates in the responses and views asserted with regard to 'death and dying'. All participants agree that counselling which includes family members, is needed for all individuals living with AIDS. However, only four participants are actively involved in a counselling process. Those who are not and have never been a part of some type of counselling, report similar views on goals and personal life perspectives. These participants view their existence as being void of goals which they equate to purpose. Loss of career, inability to have children and raise a family are painful and devastating losses. The development of new and meaningful relationships is

perceived as either pointless or potentially harmful. There is a pervasive hopelessness in their self perception.

This is not the case for those who are involved in counselling, either in a group or an individual process. These individuals speak of a minimizing of long term planning which they also describe as a change in personal priorities. A despondency and lack of purpose is not apparent. A sense of completeness and an understanding of oneself is sought and provides direction and purpose. A personal order and an effort to attain a life that is genuine is prevalent, the extent of which naturally differs with each of these individuals. Yet, there is clearly a sense of acceptance and personal control that was not obvious with the four participants who are not receiving the benefits of counselling.

Another relationship that became apparent in the analyzing of this data was the lack of awareness that individuals representing differing groups had of each other. The sample was designed to incorporate a heterogeneous group of individuals which consisted of varying lifestyle and gender. Interestingly, the homosexual participants did not seem aware that individuals outside of their group could or would be implicated or involved. This was particularly true with regard to women. The men in this study seemed to lack awareness of the involvement of women in the AIDS phenomenon.

Women indicated that they feel, for the most part, a separateness from men in similar circumstances. Susan states that while waiting in clinic " all the guys would talk to each other . . . check up on how the other was doing . . . and it was always like they didn't want to approach me or not

CHAPTER V

SUMMARY AND DISCUSSION

Summary

What are the features from a counselling perspective that shape the experience of being threatened by the AIDS virus? In recognition and acceptance of the person behind this illness, this study was designed to gain an understanding of the needs and processes encountered by individuals living with AIDS, from their perspective. The methodology used to accomplish this goal, took the form of a qualitative study and responded to three objectives.

The first objective was to document the lived experience of this small, varied sample, to enhance understanding. The second was to identify themes and personal perceptions of counselling needs from the perspective of individuals living with AIDS and finally, to provide an opportunity for these individuals to share and others to learn what it means to be living with AIDS.

Eight individuals were interviewed using a semistructured interview format, as the primary instrument for data collection. The content analysis approach provided the bases for the interpretive framework which endeavored to ascertain the participants view of the major themes and relationships inherent in living with AIDS. Eighteen subthemes (Appendix E) emerged which were further analyzed and reported as five major themes. In addition, as is often the case, relationships and patterns emerged that lay outside the parameters specified by the initial objectives.

Information pertaining to each participant was presented in a condensed form to provide a picture of these very personal and intimate disclosures in a holistic fashion. The main themes were discussed and supported by dialogue from participants. The first of these was the need for talk.

The scope of this theme included simple dialogue with another person, a caring and sharing of feelings and concerns, an expressed understanding by others of the specificities and personal difficulties peculiar to living with AIDS and self discovery and personal perspective taking through a process of confirmation and exploration with other people. This broad notion of a need to talk resembles processes inherent in counselling. The number of participants involved in some form of counselling was reported, as well as the unanimous belief that this process is essential to promote wellness.

The theme of stigma was reported with a number of associated variables. The data supported the view that the stigma experienced by individuals living with AIDS is an intra/interpersonal phenomenon that is real and pervasive. It involved subthemes of secrecy, social isolation, fear of misunderstanding, trust issues and fear of contagion. Fatigue, as a major factor affecting the daily struggle with this disease, was reported by all the participants, who are symptomatic, as well as their partners. Issues of death and dying encapsulate the fourth theme presented. Subthemes related to loss of goals, fear of dying, religious and spiritual affiliations, change in priorities and an expressed need to keep busy and avoid thinking of death comprised this category. The last major area dealt with participants' view of

the services that would best meet the needs of individuals living with AIDS. An integrated multi-disciplinary design providing a full range of services was advocated by most.

In addition, several patterns and relationships emerged from the data. The first pattern traced the apparent connection between the need to talk and views asserted with regard to death and dying issues. The resultant pattern suggested a relationship between counselling and personal growth. The second pattern suggested a lack of awareness of differing groups with each other. The data also suggested several factors that may be peculiar to the female experience of living with AIDS.

Discussion

The research findings reported in this study raise several issues that require further discussion. Interpretation, although inherent in the process used to analyze and delineate the major themes, was done within the context of the acquired data. Further interpretation was necessary to place these findings within the broader arena of psychosocial research.

A review of the related literature, as set forth in chapter II, suggested that there are features specific to the AIDS epidemic that specifically confront women and also contribute to unique psychosocial stressors for people living with AIDS. The findings in this study support some of these characteristics.

A profound sense of isolation and lack of community support, the sense of grief experienced by the loss of childbearing potential and the inability or unwillingness to become involved in new relationships were described by the women in this study who were personally infected with

HIV. This supports Wofsy's (1987) suggestion that these issues must be addressed when proposing and organizing programs for women with the AIDS virus.

The social stigma and fear associated with the contagion aspects of the disease were cited by participants as contributing to the avoidance of physical and social contact with others, including family members. The theme of stigma reported in the findings was said by participants to differentiate this disease from other terminal illnesses. Further analysis of this theme indicates that the stigma experienced by individuals living with AIDS is a function of others' misconceptions and lack of knowledge and personal trust issues stemming from fear of misunderstanding from others and uncertainty about the infectious nature of the disease. It can be described as an intrapersonal and interpersonal process that leads to pervasive secrecy and social isolation. These findings are congruent with the research in this area.

The theme of personal guilt was conspicuous by its absence in the findings of this study. The exception was one reference made by one individual whose partner has AIDS. The guilt described was not associated with this individual's choice of a homosexual lifestyle but rather behaviours relating to sexual decision making. Perhaps the absence of guilt being indicated as a factor contributing to the experience of living with AIDS was a function of the sample of individuals interviewed and the interview process. The heterogeneous group of individuals interviewed were predominantly women (six of eight) and the interview guide may not have provided a key to open this area for exploration.

Another consideration is that the association of guilt and the experience of people living with AIDS is a misconception perpetrated by the myth that AIDS is a 'gay disease' and that guilt is a function of homosexuality. The majority of known incidents of HIV infection, to date, are within the homosexual community and the media asserts that the first known case was discovered within this population, although this is not necessarily fact. These two images provide a powerful base for a bias in favour of guilt having a role in the AIDS experience and enhance the already pervasive stigma surrounding this disease.

Also of interest was that participants from a homosexual lifestyle spoke of the disease as exclusively involving themselves. Unless prompted by comment from the interviewer, they approached the topic seemingly unaware of the female population, in particular. The sample was intentionally heterogeneous to acquire information from varying lifestyle orientations. The aim was to adequately address the non discriminatory nature of the AIDS virus and thereby dispel the prevailing myth that this is a disease affecting only some minority groups. This pattern of exclusivity may suggest that this myth is further perpetrated by the groups themselves.

Another pattern reported in the findings that warrants discussion is the apparent relationship between counselling and personal growth. It must first be noted that all participants asserted that counselling was an important and necessary process to be involved in at some point. However, half of the participants had not been involved in any counselling endeavors and the other half have been a part of either a group or

individual process of counselling. The former group shared a self perception that suggested a personal hopelessness and loss of purpose. The latter group advocated a desire to understand self and learn to live with integrity. An acceptance and personal control was evident in their approach to life and in their discussion of the process involved in living with AIDS.

On first glance it appears that the second group's efforts at living with genuineness is directly related to their involvement with counselling. However, two other possible explanations exist. First, it may be these individuals' focus on self discovery brought them to counselling in the first place and that being affected by AIDS attenuated this preexisting personality characteristic. The question of which came first is relevant in ascertaining the validity of this finding.

The second possible explanation involves the sample used in this study which is mainly female. It is interesting to note that all the participants in the group not receiving counselling, were female. In addition, the subthemes that comprised the loss of purpose and profound hopelessness shared by these individuals are the same as those advocated previously in this section as forming the bases for differences in the female experience of living with AIDS: isolation, a sense of grief over loss of childbearing potential and sexuality, as well as a perceived inability to develop new and intimate relationships. Perhaps, gender differences in the lived experience of individuals with AIDS and the availability of services for women are factors which also contribute to an explanation for this pattern.

The last area of discussion involves the theme of death and dying. As suggested in the findings a large number of participants stated that they choose not to think about dying. Avoidance of issues of dying by keeping busy was suggested. This finding can not be said necessarily to suggest a fear of dying as one did not preclude the other in the determining of subthemes. Nevertheless, participants did choose not to share their thoughts and feelings, to any great extent, in this area. One would think that the theme of death and dying would be foremost when considering the experience of individuals with a terminal illness. Further inquiry in this area would provide additional insight and understanding.

Limitations of the Study

A number of limitations warrant acknowledgement. The first of these stem from the research on the AIDS virus and the effect that it often has on the central nervous system. The acquired immune deficiency syndrome dementia complex (ADC), a progressive dementing neurologic disorder, often presents with symptoms that are similar to the cognitive, affective, behavioural and somatic components seen in major affective disorders such as depression and anxiety. Although none of the participants reported being diagnosed with ADC, the reported prevalence of this disorder in individuals infected with the AIDS virus deserves mention.

The second limitation implicated the sample chosen for the study. Efforts to recruit a heterogeneous group of individuals that would provide representation from both genders and differing lifestyles resulted in a sample of six females and two males. Thus, both of the HIV positive individuals and both of the partners of the HIV infected individuals were

female. The over representation of this population could bias these results in favor of the female experience of living with AIDS. In addition, all participants in this study were involved in the Immunodeficiency Clinic at the Ottawa General Hospital and thereby recipient of similar health care services which could have an effect on their view of services needed and the design of these facilities.

The third limitation that must be noted is the personal perspective which the researcher brought to the process of data collection and analysis. The goal of this research was to consider the self perceived counselling needs of a select group of individuals living with AIDS. The researcher found it necessary to continually monitor her analysis of the data, to ensure that she was not assessing and ascribing her professional opinion of what the participant therapeutically required. The tendency to interpret the data from the researchers perceived needs is an inherent and recognized problem in this research design. The focus throughout the study was to maintain an objective perspective. Nevertheless, the design provided data that was rich with information about the lived experience of this group of individuals who are living with AIDS. The findings reported in this study represent those analyzed by this researcher. This in no way precludes the possibility that more exists.

Recommendations For Further Research

Several questions are raised by the findings of this study and are subsequently listed.

Are there differences in the psychosocial experiences of women living with AIDS? The findings of this study and related literature suggest

that there are a number of issues that differentiate their experience. Further study is warranted to ascertain the nature and scope of gender issues with regard to the AIDS epidemic.

The possible relationship between personal growth and counselling, as previously discussed, requires further study. Explanation of this pattern may lie in the afore mentioned gender differences or availability of services. The implications that this relationship has for individuals who are HIV infected, as well as counsellors, directly effects how people manage and live with AIDS.

Extensive research is also suggested by the findings in the theme of death and dying. Questions pertaining to fear and avoidance may stem from counselling needs being unmet or an uncertainty with whether or not infection with HIV will lead to the development of AIDS. Whatever the case, there is an elusiveness to the data secured in this area that begs attention.

The last question may be intrinsically found in the theme of stigma. Is guilt a factor contributing to the stigma described by individuals living with AIDS? Is it a function of bias fed by preconceptions associated with stigmatized minority groups such as homosexuals and intravenous drug abusers or an intrapersonal occurrence rooted in one's own moral philosophy?

Concluding Statement

Acquired immune deficiency syndrome is everyone's crisis, no one is immune. This epidemic has mutated and exploded to all segments of society. Although AIDS is still in its early stages, it is apparent that the future will entail greater involvement on the part of counsellors, educators,

psychologists, social workers, nurses, all health care professionals and the world at large.

AIDS is a particularly cruel illness; it devours the very system the body uses to defend itself, leaving its victim prey to all invaders. The systemic and psychoneurological complications that accompany this disease are profound and devastating. It is multi-stigmatized, lethal and transmitted through a means of personal expression that is fundamental to humanity. The complexity of the AIDS crisis is overwhelming and counsellors and caregivers do well to query their role in meeting the demands presented by this overwhelming disease of the body's immune system.

A cure is not presently a reality but care is within our grasp and, as such, the involvement of health care professionals is crucial. For counsellors to work effectively, they must understand and be able to empathize with the special issues that people living with AIDS must face.

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APPENDIX A

Chart of Participants

HIV +	AIDS	Partner HIV+	Partner AIDS
Lucie	Susan	Arlene	Michelle (HIV+)
Lynne	Andre	Simone	SHAWN

APPENDIX B

Interview Guide

INTERVIEW GUIDE

The interview process involves three steps: a review of the goals and purpose of this study, obtaining informed consent, and semi-structured interview consisting of eight core questions.

1. The first step in the interview process will be to review the goals and purpose of this project. The following statement to the subjects is designed to set the parameters and provide an understanding of the process : "The purpose of this study is to look at and document the psychological factors (mental/emotional/spiritual and behavioral) and the counselling needs of individuals that are seropositive or have developed AIDS and their significant others.

The goal is to gain an understanding of your needs from your perspective; to pull out the aspects of your lived experiences so that caregivers and the counselling community may learn from you in order to better serve and aid you and those in similar situations.

Your knowledge of what would and could benefit you and others is invaluable to an understanding of your needs and the providing of psychotherapeutic and counselling assistance and intervention."

2. The second step is obtaining informed consent. The procedure as outlined in the ethical section of research format will be adhered to and are outlined on the consent form .

3. The participant will then be asked to comment on a series of core questions from which the interviewer may branch off to explore in depth. As accurate and complete information is desired , this provides the

opportunity to probe for underlying factors or relationships which are too complex or elusive to encompass in more straight forward questions.

The following is an outline of the 8 core questions:

1. What happened for you when you found you were seropositive/ diagnosed with AIDS / or that your loved one was affected by the AIDS phenomenon?

   The focus in this area will attempt to trace the emotional content, interpersonal relationships and counselling experiences through to the present.

2. What did or do you NEED from the significant person(s) in your life? (family, the helping profession, medical practitioners and others relevant to the situation)

3. What limitations have been imposed on you? (social / psychological stressors)

4. Is there a religious dimension to what you're going through? Has your view of disease, death and dying changed? How?
   (spiritual beliefs/needs)

5. Are there differences in the AIDS phenomenon and other terminal illnesses?

6. What has been your BEST and WORST experience since first learning that . . . ?

7. How would you design a program to help people like yourself; what would be the first 4 priorities?

8. In addition to what you have already shared, what in your view do counsellors attempting to assist those in a similar situation to yours need to be aware of or to know ?

APPENDIX C

Consent Forms

CONSENT FORM
(video)

I agree to the filming of this interview taking place on the _____ day of _____, 19____ at _____ with _____ and understand that it will be used for research and educational purposes.

My right to confidentiality and anonymity have been explained to me and I do recognize that this process does indeed infringe on these rights. With this understanding, I consent to the use :

1. my first name only
2. my name in full
3. a pseudonym only

I, additionally understand that my appearance will not be altered in any fashion, unless otherwise stipulated in the additional criteria section of this form.

I acknowledge the right to terminate this process at any time just as the researcher may terminate this research in the interest of the subjects, the project or herself.

I wave all rights and responsibilities pertaining to the producing, editing and distribution of this film recognizing that the goals of this research project are as follows:

1. To gain an understanding of the psychological, intra/interpersonal factors related to the HIV virus and related diseases, from the perspective of those effected and their significant others.

2. To document the lived experiences of a small, varied sample of those individuals affected by AIDS in an efford to dispel prevailing misconceptions, specifically within the caregiver, counsellor community.

3. To identify the themes and personal processes from the perspective of individuals directly affected by the AIDS phenomenon.

4. Provide an opportunity for persons affected by the AIDS phenomenon to share their knowledge and lived experiences in a meaningful and constructive fashion.

Additional Criteria (if any):

WITNESS:

Name:_____

Address:_____

_____

Sign:_____

PARTICIPANT:

Name:_____

Address:_____

_____

Sign:_____

Researcher (Contact Person):
Anni M. Madott
University of Alberta
Department of Educational Psychology
6-106 Education North
Edmonton , Alberta
T6G 2G5
403-436-6806

CONSENT FORM II
(audio)

I agree to the audio taping of this interview taking place on the _____ day of _____, 19____ at _____ with _____ and understand that it will be used for research and educational purposes.

My right to confidentiality and anonymity have been explained to me and I do recognize that this process does indeed infringe on these rights. With this understanding, I consent to the use :

1. my first name only
2. my name in full
3. a pseudonym only

I acknowledge the right to terminate this process at any time just as the researcher may terminate this research in the interest of the subjects, the project or herself.

I wave all rights and responsibilities pertaining to the producing, editing and distribution of this tape recognizing that the goals of this research project are as follows:

1. To gain an understanding of the psychological, intra/interpersonal factors related to the HIV virus and related diseases from the perspective of those effected and their significant others.

2. To document the lived experiences of a small, varied sample of those individuals affected by AIDS in an efford to dispel prevailing misconceptions, specifically within the caregiver, counsellor community.

3. To identify the themes and personal processes from the perspective of individuals directly affected by the AIDS phenomenon.

4. Provide an opportunity for persons affected by the AIDS phenomenon to share their knowledge and lived experiences in a meaningful and constructive fashion.

APPENDIX D

Interview Transcript -Susan

APPENDIX D

INTERVIEW WITH SUSAN

Q: TELL ME A BIT ABOUT WHAT HAPPENED FOR YOU WHEN YOU DISCOVERED THAT YOU WERE HIV POSITIVE OR YOU HAD AIDS. HOW DID IT COME ABOUT?

A: O.K. hum I was engaged and living with a hemophiliac and he had been treated with factor eight and he was then later diagnosed as having the antibody and then went on to develop AIDS About a year before he died I went in for testing as well and found out that I had the antibody but that's all that happened, and about four or five month after he passed away - September,86 about three or four months afterwards then I developed my first pneumonia and was diagnosed with AIDS..

Q: SO YOU'VE HAD AIDS SINCE 86?

A: YES. Well it's been three years and three months since I was diagnosed.

Q:SO BACK THEN WHEN YOU FIRST FOUND OUT ABOUT ALL THIS -WHAT WAS HAPPENING FOR YOU?

A:It was shocking when we first learned that he had it. We wondered because he had had a brother that had past away a year and a half before that of AIDS ,all the brothers where hemophilias and once he just started to get sick all of a sudden --a normally healthy guy , we sort of suspected that maybe that's what it was, and then when I went in , I sort of knew that I would probably be diagnosed as having the antibody. So - but still there's the time when you go in and they say yes - there's always the yes or no, but what if they say yes.

Q: WHAT WAS THERE EMOTIONALLY FOR YOU, WERE THERE SUPPORT SYSTEMS?

A: Not a whole lot because when I was diagnosed at that point he was very sick and I don't know , I guess I never found time to find something for me. I was to caught up in him because he was extremely extremely sick. He didn't do well from as soon as the first symptoms started. It all happened so fast and got bad really quickly, so it was not a whole lot but - I'd still sit back at the end of the day and think- boy seeing what he is going through, I hope I don't ever come to that point where it gets this bad. And we are not a overly close family so there was not really a whole lot.

Q: SO WHO HAVE YOU GOT NOW?

A:Well my sisters and my brother and my father they're all still living and I was quite close to my mother but she passed away the year before Frank did and uh she knew I had tested positive and that made problems later on. And I was pretty close to her so when I lost her it sort of shock me up. You know I couldn't really talk to anyone. I guess my older sister is the one I'm closest to now. My father doesn't really involve himself a whole lot only because I don't go to him and he's older and in poor health and I'd just rather not put more on his shoulders. So I guess the one I'm closest to is my older sister, but there is still a lot that she doesn't understand about it.

Q: HAVE YOU EVER HAD ANY COUNSELLING EXPERIENCES IN THE LAST THREE TO FOUR YEARS.

A: Actually I think the only time was really a month after Frank passed away. I just let myself go, I didn't do anything. I didn't want to eat. I didn't want to do anything. And so I spoke to the priest at the church ST.

Anthony's. And we talked for a bit and he said just sort of let it be for now and eventually things would make sense. But I was probably just really angry at everything. And I didn't understand how something like that could happen to someone so innocent. But he said to give it time but other than that not really any other counselling.

Q: SO YOU WORKED TROUGH IT ON YOUR OWN.

A:Ya I sort of got like I took about a month and a half off work then I got back and I got back to work.

Q: ARE YOU STILL WORKING NOW?

A: Yes, it helps to keep busy because even when I come out of the hospital the like two or three weeks I have to spend at home afterwards. I just go crazy at home because I can't just sit there being sad or stay just thinking about it. So it's better therapy for me anyway to get back out and be with people.

Q: DO YOU LIVE ALONE?

A: Umhm, by choice. I love living alone.

Q: DO YOU?

A:Ya it's the kind of person I am.

Q: WHAT DO YOU NEED FROM PEOPLE, LET'S SAY FROM SIGNIFICANT OTHERS IN YOUR LIFE - FROM FAMILY?

A:Just a little bit of understanding that if i'm tired and can't do something that they accept that . I am lucky working with his family, and they are pretty lenient with regards to work and stuff. They know if I call the day before and say well tomorrow I'm going to be late because I'm doing an interview. Then they say fine you know that comes first and if I have to

leave for an appointment or if I call in sick and said I don't feel sick but I do feel under the weather like I'm having trouble getting out of bed. But they are understanding and like nobody rushes me and if I feel like going slow or if I feel like being alone to just leave me alone and let me be.

Q: WHAT ABOUT HELPING PROFESSIONALS OR MEDICAL PEOPLE-WHAT DO YOU NEED?

A: Well I've talked quite a bit with the nurses when I come in for my treatment. I come in three times a week so we talk about real things or something that might be troubling me.

Q: DOES THIS HELP?

A: Oh yes. Like there are two nurses in the clinic that are special - so sweet and we'll talk about baseball, we'll talk about this and that but then we'll also talk about like the little things. They'll notice if I come in a little sad and try and find out what is wrong

Q: AND TAKE KIND OF A PERSONAL INTEREST.

A:UMHUM

Q:WHAT ABOUT KNOWING ABOUT YOUR MEDICAL CONDITION?

A:I did quite a bit of reading especially when Frank was sick, but then since than a lot more has come out and I guess pretty much just what ever there is in magazines and newspaper and broad cast but aside from that not a lot.

Q: SO IN TERMS OF NEEDS YOUR TALKING ABOUT PEOPLE WHO YOU CAN TALK TO AND UNDERSTANDING YOUR SITUATION ?

A: Yeh

Q: DO YOU FIND THAT THERE IS PREJUDICES AROUND YOU HAVING AIDS?

A:At one time there was a lot of prejudice because I was still, I had a full time job some where else and I worked with my fiance so when he pasted away at 27 years old there was a lot of suspicion to what and why and everything and you could really hear the rumors going around and the first time I went into the hospital and spent time in the hospital - what's happening -like this girl use to run almost ten miles a day then all of a sudden I get sick and go in the hospital for a month and a half.

So then, at that time, there was prejudice but now I have to say there is not a whole lot because I don't - I haven't really been social or going out very much I don't know . I meet people and I sort of start to get close to them but if it gets to close I back away because I don't really want to share my secret with any one body only because a lot of people don't understand what it's about and it's not and you can't get it by touching me or talking to me or what ever.

Q: SO IN TERMS OF MAKING NEW FRIENDS OR THINGS LIKE THAT- THAT'S NOT SOMETHING THAT HAS HAPPENED FOR YOU?

A: I have met like a few really good people. Like I don't get out as much any more and stuff.

Q: WHAT ABOUT LIMITATIONS OR DIFFERENT CHOICES YOU HAVE HAD TO MAKE SINCE THIS HAS HAPPENED?

A: I guess the biggest things was I guess my working environment and stuff. I've had to change around a lot because of the hours. I have to come in here and clinics and my appointments and every thing else. I sort of, you know, I sort of have to take this job. I was offered a couple very good

jobs at two of the larger hotels here in Ottawa the Sheradon and the Westin hotel but because of the hours and stuff I couldn't and I have to be where I could tell them I have to leave because of medical reasons . That sort of stopped me in my career because I used to work in a kitchen , a very large kitchen managing kitchens and stuff so this has sort of limited me. I wanted to go on and get better and learn more so it wasn't so great . I get so tired and stuff.

Q: THAT MUST BE HARD?

A:Well I have always been very active I've always had at least two jobs like a full time and a part time and enjoyed it .

Q: IN TERMS OF RELATIONSHIPS HAVE THERE BEEN LIMITATIONS THERE?

A: Yeh, I find that there are very few people I trust to talk about my situation . I've chosen my friends carefully and sometimes I've met people or that I've started to become closer to and I didn't quite know how to talk about it and some male interests this happened with and when it comes to the point ,you know, where it starts to become a little closer then I choose not to tell them and deal with it - I just back away and run.

Q: SO THEY'RE LEFT NOT KNOWING WHAT HAPPENED?

A: Ya Like there was someone very nice that I had been seeing and then it became a little close and he was just the sweetest person and every thing but it was getting just to close and we started talking about ,well you'll have to come and see my mom and dad and talk to my mom and dad about our future and I don't think they ever understood why - it's just something I

guess mainly if they didn't know how to deal with it - I guess he could really be scared off by it so I just couldn't.

Q: IS THERE A RELIGIOUS DIMENSION TO WHAT YOU ARE GOING THROUGH?

A:As in ?

Q: AS IN - HAS YOUR VIEW OF DYING OR DEATH CHANGED ?

A: When Frank was alive we had become very spiritual and we went to church and we prayed. There was a long time where he didn't know that he was dying, he didn't know he had the disease because his mind started to go and he didn't notice, but we knew so we where trying to do everything we could. The only means we have is spiritually. So I poured everything I had into it ,day and night like I'd read by his bedside, get him food or ask the priest to come and see him and what ever but when he died -I said ,gee this really does happen to good people and I said that's not right and I never went back to the church- like I just couldn't just because I could not understand how something like that could happen and with out being able to stop it or slow it or make it easy because he died a very difficult and a very long one and very very sad death and I thought -gee , it wasn't as if I was asking God for favors but if he could have made it a little easier like I didn't expect something in return for my prayers but I didn't expect him to make it that cruel. So since then I never went back.

Q: SO DURING THAT PERIOD OF TIME WHO WAS THERE FOR YOU LIKE DID YOU FIND THAT THE PRIEST OR THE RELIGIOUS PEOPLE WERE HELPFUL ?

A: They could have been more helpful if I had let them in more. If I really really talked to them deeply about how I felt I sort of just kept it border line

and talked about some things but not as much as I should because he probably would have helped me more but other than that no. And my family, at the time, I was just so involved with working two jobs and taking care of him and hospitals that I just - there just wasn't any time and my family at the time weren't as close as they are now, so there wasn't really one of his brothers I was especially close to and we just thought O.K. we have got to get through this we have got to get through and he was someone I really could talk about everything to.

Q: DID HE PASS AWAY AT HOME?

A: No, he was in the hospital - he was just in for a month and a half before he died so his mind was really gone by that time.

Q: SO SINCE THEN YOU HAVE STAYED AWAY FROM ANY KIND OF FORMAL RELIGION?

A: UMHUM.

Q: WHAT ABOUT PERSONALLY, IN TERMS OF YOUR OWN SPIRITUAL FEELINGS ABOUT IT, SEPARATE FROM THE CHURCH OR SEPARATE FROM ANYTHING ORGANIZED?

A: I think it's just been that I just move quickly and I don't really sit back to think about what's going on because if I do then I get depressed and I think well - many times I feel that I have no more goals like why bother putting money into a savings account when I'll never get to spend it on something that I want or I can't think of having children or a close mate so that's hard because you know sometimes if I sit there too long and I think about it I think well why am I even bothering taking the treatment - like

another year or so - is it worth it ? So I keep telling myself-they'll come up with something.

When I really look at my life there really is no goals there's nothing towards my future that I'm building myself. And I guess it's just because of what I have seen and been through you know I think well it's not worth the effort but I still like keep going and I am a very happy person and very energetic and I enjoy life but sometimes I think when's the next time I'm going to get sick or when's the next time something is going to happen. And that's hard too because when you come into the hospital - it just so much like - I think the last time I came in I had a pneumonia in April and when I came in I felt worse then the other pneumonia I had, so when I came in the hospital I was two to three weeks just laying there dead and just thinking I just couldn't wait to get out and get going again, which was good because it probably healed quicker- it got me out of there that's for sure.

Q:SO IT HELPS YOU THEN TO JUST KEEP RIGHT ON GOING AND NOT THINK ABOUT IT. SO THE WHOLE ISSUES AROUND DYING, AROUND DEATH, AROUND THOSE KIND OF THINGS, YOU PUT A SIDE?

A: I do but there are some times where I do get scared and I think - what kind of death is it going to be - lying around in the hospital and sometimes it does get kind of scary and I don't really know if I'll be prepared for it or what to do with it?

Q: OR WHAT TO DO WITH IT?

A:UMHUM Because if it ever comes to that point like I don't know if I'll be well enough to know what is happening. It scares me, it scares me the ways of dying like how it might be - painful or I think of not being able to breath

like if I was in that kind of situation or something I would hate to go like that. (pause)

When I die don't want to leave my family in any financial mess, you know I think about that too and think well maybe I should plan ahead for it so it will be done when the time comes and stuff. Not to be gory or I'm not thinking about my death but I just know what it was like to go through it and not be prepared for it.

Q: HOW HARD IT IS ON OTHERS- YOU MEAN?

A: Ya - I know when your in mourning, you need time to mourn not look after bills and get back to work right away, you need time.

Q: ARE THERE DIFFERENCES BETWEEN HAVING AIDS OR OTHER TERMINAL ILLNESS.

A: I guess just mainly it's harder to relate to people because you could talk to someone and tell them you had cancer and they'd say poor you and feel sad but if you say you have AIDS there's always that little bit of pulling away out of fear and what not , so that's a bit harder because that is probably why there's less people I can talk to about it because I just don't know how people would accept it or deal with it so it becomes a bigger secret.

Q: WHAT ABOUT HELP - RESOURCES THINGS LIKE THAT?

A:Well there's quite a bit right here at the hospital like if I wanted it the nursing staff they're good. At one time when I was unable social worker provided help and they covered the drugs which were very very expensive at the time and stuff and that was great. It could have been more - I mean when I'm off for a month they don't give you a whole lot to get by on and they look at your financial situation - they look at you rent, your hydro but

in a way it's not their problem it's your payments and your telephone and everything else but a couple of times like I had a lot of outside debts and I had to borrow a lot of money and just get in deeper and deeper and then you're pushing yourself more and more just to cover the extras and stuff.

Q: WHAT HAS BEEN YOU BEST AND WORST EXPERIENCES SINCE THIS BEGAN?

A: Well the worst was Frank dying and I guess the best is just coming into this clinic.

Q: JUST COMING IN TO SEE PEOPLE.

A: Yeh, just saying I'll pull through this one again you know.

Q: ALMOST LIKE A DAILY CHALLENGE

A: Ya it's like you know, I come back and start over and over and I just look for the day where O.K. I don't have to come in

and take it anymore it's finished over with.

Q: IF YOU WHERE GOING TO DESIGN A PROGRAM TO HELP PEOPLE LIKE YOURSELF; WHAT WOULD IT LOOK LIKE?

A: Well there would a lot of help I guess in the same way as in the hospital - a lot of counseling - hum, if you like needed someone to talk to or if you where going through let's say a rough spot and like even financially that they could sit down and be real and more personal and help you sort it out and actually deal in detail with it and say O.K this is the people you go see- maybe this could help you or this could like - a little bit closer than just giving you welfare.

Q: SO ACTUALLY HELPING YOU SORT IT OUT

A: Ya looking at each little problem that there might be and see if you can get through it . I guess aside from that - I don't know like - I come in quite

a bit for treatment and stuff but if it could be made a little bit easier according to hours and stuff. I have to get up very early in the morning and then I have to go to work after my treatment so it gets to be a long day and when I tired in the morning it is very hard for me to get out of bed and make it here in the morning so better hours or one of the treatment I'm on - the intravenous medication - they have been talking and talking about us doing it at home. It's a very simple procedure and they have been talking about doing it at home and when I was in the hospital in September they where saying o ya probably in a week or two you can do it at home still now there's no date in mind of when we are going to start. So coming in here three times a week plus all the other appointments , doctor and everything else it's quite a bit of running back and forth and that really disrupts your life - let alone having to explain to people where you have to be . I'd rather be working and making some money instead of laying here so - I wish things - that they would move it along a little quicker and really think about the patients that have to come in here every day. A lot of patients that have to come in 5 times a week for this treatment - like even if they have something like that close to there home that you come even just go in and they are talking about having a V.O.N supervise at home for the first while but even if there was a closer place - like even if there wasn't set times just make life a little bit easier and just I know it's difficult and there busy people to but .

Q:SO WE HAVE GOT YOUR PROGRAM HERE AND WE'VE GOT COUNSELLING KINDS OF THINGS AND AVAILABILITY OF TREATMENT AND THOSE KINDS OF THINGS

TO MAKE IT EASY FOR PEOPLE ANY THING ELSE YOU WOULD HAVE IN THIS PROGRAM?

A: Well , financially help for patients when they come out of the hospital cause it's going to be the hardest time. You're so far behind in your payments and grants and everything else. Then you get a certain amount from - if you apply for welfare and if it's not enough to cover then you fall deeper deeper. I found myself at times when I would be rushing myself to get back to work because I had to and some times the needed to rest or take it easy or you know you're going to end up right back here cause you are weak right now and your system is down -so you need to take it easy and stuff. So I wish there was something more that could be done in that respect. I guess that just depends on each persons expenses and stuff.

Q: HAVE YOU EVER BEEN IN CONTACT WITH THE AIDS NETWORK IN OTTAWA?

A: No , the only time was just after Frank passed away - I had called then and asked them if I could be a volunteer if there was anything I could do to help and they called me back and said no because you are a female

Q: NO

A: They said I don't think you could relate to our patients that the majority are men. I wanted help other people that are going through it because I had seen and at that time I was very healthy and very energetic and they just said no and I thought well I'm sure there was some thing I could do- I wasn't asking to do a big job maybe just some one to talk to when you are in the hospital or a friend or anything and they just said no.

Q: THAT SOUNDS LIKE WONDERFUL PLAN YOU HAD IN MIND.

A: Well I thought it might help me go through it because I was in mourning I guess you would call it for quite a few months. I just didn't understand it. I felt sad for people who had to go through it all cause I was very healthy then at that time after he died.Well at least a few months - anyway- I thought maybe if I got back on my feet and maybe there is something I could do or maybe I'll help now because eventually maybe I'll need the help and you it would be nice to have a friend or something going like when they said no I just thought maybe that they would be more than anxious to have help but they said no, they didn't' think I could relate to people.

Q: DID THEY OFFER YOU ANYTHING ELSE?

A: NO, Just hung up the phone that's it .

Q: AND THEY KNEW YOU WHERE HIV POSITIVE?

A: Ya, I told them I said I have been diagnosed myself but right now I'm very healthy. I've had no problems at all and I'm very healthy and I have been through it with someone so I have a good understanding of what it's all about and I would like to talk or just do anything - go do groceries for someone you know because I know how hard it is to do that when you get out of the hospital and you don't have any milk in the refrigerator and you really can't get up like I mean you really can't get up to get it- so you just go without . But I thought even just to do something like I'm not talking about me counselling someone or doing anything like that because I'm not - I wouldn't know how to do that but I mean I 'm sure there could have been a few little things that I could do or even maybe even talk to other females who might have been scared or just sit with them.

Q: DO YOU THINK THERE IS A DIFFERENCE BETWEEN BEING A FEMALE IN THIS SITUATION OR BEING A MAN?

A: Yeh, even when I come to the clinic and I sit out there and there would be 50 men that I would be sitting there like what is she doing here cause I don't look it . I look pretty really good and stuff like that and it was hard and all the guys would talk to each other and check up on each other- how the other one was doing and stuff and you would notice it - like men would sort of sit with the men and they would talk but I guess they just weren't sure my situation and if I was positive or not and it was always like they didn't want to approach me or talk to me I mean your just sitting there for an hour and a half next to these people and nobody would really talk about it or just among themselves and stuff so.

Q: DO YOU THINK IT WOULD BE HELPFUL FOR WOMEN TO GET TOGETHER?

A: They have started to get a clinic or I guess you could call it a clinic together here and for females - to talk about it but for me it always ended up on the days or the nights that I was working and so I was not able to attend but they have had two or three but they have said that for some reason they have only had one that showed up. It was only because I was working otherwise I would have shown up.

Q: ONE WOMAN SUGGESTED A PHONE NETWORK WHERE YOU WOULD KNOW THE NAMES OF THE OTHER PEOPLE WHO ARE IN A SIMILAR KIND OF SITUATION AND YOU COULD CALL AND TALK FOR HALF AN HOUR OR WHAT EVER OR MEET FOR COFFEE WHEN YOU BOTH HAVE TIME . WHAT DO YOU THINK ABOUT THAT?

A: Yeh, Some thing a little bit more personal - just O.K today I am feeling a little sad and maybe it would be nice to talk to some one but not everything as clinical and set up and organized .

Q: I HAVE HAD ANOTHER PERSON ACTUALLY ANOTHER WOMEN TELL ME THAT SAME KIND OF THING , THAT THE BEST WAY TO GET AROUND THIS NEED FOR TALKING AND SHARING THAT YOU'RE TALKING ABOUT TOO IS TO DO IT IN AN INFORMAL WAY. SHE WAS SUGGESTING THINGS LIKE HAVING LITTLE GET TOGETHERS IN SOMEONE'S HOME - INVITING A FEW PEOPLE OVER THAT ONCE YOU GOT TO KNOW THEM A BIT THAT KIND OF THING, BETTER THEN COMING INTO THE HOSPITAL TO HAVE A GROUP SESSION

A: And there is often at group things where they have - you come in and there's - it's not that I don't appreciate their work - but there's always the social worker that steers the conversation and the topics and stuff and I don't think you could speak as close to the heart as you would if you where two females on one to one. The same thing there's always the other person that's listening taking notes that makes me uncomfortable.

Q: IT TAKES AWAY FROM THE PERSONAL PART?

A:It's like we are becoming a survey - in a way that sort of makes me shy away a little.

They have come a long way though I can remember back when he was sick in 84 in the hospital and you would have to wear a cap and gown and gloves and boots to go in the rooms to say hello. You've been with someone already for 6 years and was intimate with and I would have to go through all of this in the hospital - all these great big flashing signs on the doors and what ever person and - it has come a long way - like I can even

remember about a year ago I was in the hospital and they put these signs on the doors - awful signs over your bed saying precautions wear this and wear that and stuff like that and I just said wow I hated it because people who don't know about me that come to visit me say well what's the precautions about --uh uh well- Even the last time I was in the hospital and I told the nurse about it -they had put a sheet out in the outside of the room and on it had just about everything about me - anybody who walked by - I don't really want everyone to know about my situation and it's not really any of their business unless I chose it to be and so they have stopped doing that now .

Q: SO YOU HAVE GOT PEOPLE WHO STILL DON'T KNOW??

A: O ya.

Q: THAT MUST BE HARD TO KEEP THAT SECRET?

A: It is because like some times I have to come up with some dandy excuses to get out of going some where because I feel tired - because they might not understand or little things that happen or if I get a funny rash or reaction to something or other.

Q: CAN YOU THINK OF ANY THING ELSE YOU WOULD LIKE TO SHARE THAT COUNSELLORS NEED TO KNOW TO HELP PEOPLE IN YOU SITUATION??

A: All I was going to say is - I hope that if it ever comes to a point where I'm getting sicker and if the doctors could be honest. Let's say there looking at my blood or they know how my counts are doing and stuff I wouldn't really want to wait for something awful to happen but they can tell me and be honest. I hope they'll always be a honest relationship between me and my doctors - that they could tell me when things are getting worst and just so I

can be ready to deal with it myself. So if I'm ready for it - I'm mentally prepared you know like thinking there is only so much they can do or they can't do but so far it has been great

Q:HONEST AND UP FRONT.

A: Like I would rather know what I am going to be facing and be ready for it - stand on guard -I guess probably most everything relates back to my relationship with Frank and what I had to see him go through and in the way that he did and be ready for not having the time to go out and enjoy or do what ever it was always rush rush rush .

Q: I REALLY APPRECIATE YOU COMING IN TO SEE ME- YOU.'VE BEEN VERY HELPFUL!

A: It was nice talking to you . You made me feel very comfortable.

APPENDIX E

Subcategories Of Themes

SUBCATEGORIES OF THEMES

	SIMONE	Arlene	Michelle (HIV+)	Shawn	Lucie	Lynne	Susan	Andre
	PARTNER - HIV	Partner- HIV	Partner-AIDS	Partner-AIDS	HIV+	HIV+	AIDS	AIDS
Involved in Counselling	no	yes	no	yes	no	yes	no	yes
Understanding		√	√	√	√	√	√	√
Need for Talk	√	√	√	√	√	√	√	√
Social Isolation			√	√	√		√	√
Secrecy	√		√	√	√	√	√	√
Fear of contagion	√	√	√	√	√	√	√	√
Fatigue			√	√	√		√	√
Work/Career			√	√	√		√	√
Trust Issues			√	√	√	√	√	
Fear of Misunderstanding	√	√	√	√	√	√	√	√
Religious Affiliation	yes	yes	yes	no	yes	yes	no	no
Keep busy/Don't think	√		√		√	√	√	√
Loss of goals	√		√		√		√	
Change priorities		√		√		√		√
Fear of dying					√		√	
Services	√		√	√		√	√	√
Female differences		√	√		√	√	√	√
Personal/less clinical	√		√	√	√	√	√	√
Honesty		√	√	√		√	√	√